

Family Perspectives of Nursing Strategies to Facilitate Transition from Curative to  
Palliative Care in the Intensive Care Unit

by

Judith Ann Adams

Nursing

Duke University

Date: \_\_\_\_\_

Approved:

\_\_\_\_\_  
Donald E. Bailey Jr., Supervisor

\_\_\_\_\_  
Ruth A. Anderson

\_\_\_\_\_  
Sharron L. Docherty

\_\_\_\_\_  
James A. Tulskey

Dissertation submitted in partial fulfillment of  
the requirements for the degree of Doctor of Philosophy in Nursing  
in the Graduate School  
of Duke University

2013

ABSTRACT

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## Abstract

**Problem:** Family members of patients dying in the ICU are faced with agonizing dilemmas, the consequences of which might haunt them for a lifetime. Providing these family members with meaningful support and information is imperative. Nurses, by virtue of the time spent at the bedside and knowledge of patient and family needs, are in a unique position to support family members. The literature provides ample studies of how nurses perceive they are involved in EOL decision-making and several studies describing what family members perceive that they need from health care professionals in general. What is lacking is literature that describes the family members' perceptions of the specific strategies that nurses use to support their decision-making and how family members respond to these strategies. Because nurses might act on instinct, the strategies they use might or might not be helpful to family members. This study builds on prior work by exploring in greater depth the involvement of nurses in EOL decision-making, the specific strategies that family members perceive nurses using, and how family members respond to these strategies. This study aims to explore how family members respond to nursing strategies to support EOL decision-making, including family members perceptions of the strategies nurses use, how these strategies change over the trajectory of decision-making, and how these strategies affect their ability to make decisions consistent with the goals of the patient and their ability to cope with the

stress of making EOL decisions.

**Methods:** Chapter two describes a systematic review of the literature that was conducted to define areas where research is needed. Chapter three describes a pilot case study that was conducted to determine the feasibility of conducting a prospective longitudinal study of family members making EOL decisions for their loved one in an ICU. Chapter four describes a prospective, longitudinal, qualitative descriptive study. In this study, the PI identified ICU patients who were likely to need complex decision-making and used narrative style interviewing techniques to explore the family members' perceptions of the strategies nurses use and the effectiveness of these strategies. Participants were recruited from a 16 bed adult medical ICU and a 16 bed surgical ICU at Duke Hospital, a tertiary care university hospital system.

**Results:** These studies identified three roles enacted by nurses: information broker, supporter, and advocate. While enacting these roles, nurses used a myriad of strategies categorized into five approaches: Demonstrate concern, build rapport, demonstrate professionalism, provide information, and support decision-making. This study provides empirical evidence that when interacting with family members of patients who were transitioning from curative to palliative care in the ICU, nurses used strategies that helped family members cope, to have realistic hope, to have confidence and trust, to prepare for the impending loss, to accept that their loved one was dying,

and to make decisions. These findings also suggest that nurses were able to demonstrate flexibility in the use of the strategies, responding to the needs of the family members.

Although nurses used many helpful strategies to support family members, some nurses used strategies that negatively affected the family members' trust and confidence in the nurses, increased their difficulty coping, and, in some cases, might have delayed decision-making. Few of these strategies have been previously described in the nursing literature.

**Summary:** Knowledge from this study will pave the way for developing expert nursing practices for intervention studies targeting the areas identified as important by family members, most likely to improve their ability to make decisions on behalf of their loved one and to improve their well-being, and feasible in ICU environment.

## **Dedication**

To Christine, my partner and best friend, your support and encouragement gave me the courage to finish this. Thank you.

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# **1. Introduction**

## **1.1 Problem**

In the United States 50% of people who die in hospitals, die during or after a stay in an intensive care unit (ICU) (Wunsch et al., 2009), and two thirds of ICU deaths involve a decision to limit treatment, either by withholding or withdrawing life-supportive therapy (Balboni et al., 2013; Balboni et al., 2007; Desteno, Gross, & Kubzansky, 2013; Prendergast, Claessens, & Luce, 1998; Prendergast & Luce, 1997). Because of the severity of their illness and the nature of treatments, up to 90% of ICU patients lack decision-making capacity (S. Cohen et al., 2005; Delgado et al., 2009; Goold, Williams, & Arnold, 2000; Hiltunen, Medich, Chase, Peterson, & Forrow, 1999), leaving family members to make these difficult decisions. These family members face significant burden, including fear of their loved one suffering, fear of giving up too soon, and lingering feelings of doubt, regret, and guilt (Braun, Beyth, Ford, & McCullough, 2008; Kirchhoff et al., 2002). These vulnerable family members rely on healthcare professionals to guide them through the decision-making process.

Nurses in the ICU are well positioned to support family members as they make decisions because they spend extensive time periods with the patient and family, providing not only technical care but intimate personal care that allows nurses to

develop trusting relationships with patients and families and to assess their needs (Puntillo & McAdam, 2006; Thelen, 2005). Nurses are able to observe the responses that family members have to the decision-making process. Nurses thus gain a unique perspective that places them in a position to provide support to family members who are making end-of-life (EOL) decisions.

The SUPPORT (1995) study was a landmark study that set the stage for contemporary research about EOL decision-making. Phase I of the SUPPORT (1995) study, a multi-site investigation into the delivery of EOL care, demonstrated that poor communication about EOL issues resulted in many patients receiving life-sustaining care that they did not want and experiencing moderate to severe pain at the end of life. Based on the findings from the first phase of this study, the SUPPORT investigators designed a comprehensive nurse facilitated intervention aimed at improving the medical decision-making and outcomes for critically ill patients by improving communication (1995). The specially trained SUPPORT nurses provided physicians with prognostic information based on a scoring algorithm as well as with information about preferences for cardiopulmonary resuscitation (CPR) gathered from patients and/or surrogates (SUPPORT, 1995). The assumption was that, when given this information, physicians would change how they practiced, EOL care would improve, and use of inappropriate resources would decrease. However, the intervention did not

improve the study outcomes of: (a) the length of time to obtain a do not resuscitate (DNR) order, (b) physician knowledge of patient preferences for CPR, (c) patient and family reports of pain, (d) length of stay in the ICU, and (e) resource utilization (SUPPORT, 1995).

Subsequent to the presentation of these disappointing findings, leaders in the field of EOL care have noted that the SUPPORT investigators erred by making several assumptions not based on empirical evidence. For example, the investigators assumed that providing a computer estimate of prognosis would change physician behavior, not taking into account the fact that physicians' predictions are as accurate as computer models (Parrillo, 1996; Prendergast, 1996). Another assumption was that information alone is sufficient to change behaviors, which behavioral science research has shown to be untrue (Solomon et al., 1996). They also assumed that the presence or absence of a DNR order would capture a person's EOL preferences (Prendergast, 1996). Others pointed out that the SUPPORT intervention used computer models and nurses to substitute for physician communication and that physicians were not given the tools they needed to communicate effectively with patients and family members (Donnelly, 1996; Sachs, 1996).

Although the SUPPORT intervention did not improve the study outcomes, subsequent analyses of narrative data from this study has demonstrated that nurses



played a significant role in supporting the patients and families and guiding them toward a readiness to withhold or withdraw care (Hiltunen et al., 1999; Murphy, Price, Stevens, Lynn, & Kathryn, 2001). Subsequent nursing research in EOL care suggests that involving nurses in EOL decision-making might be beneficial to family members; however, descriptions of how the specific strategies that nurses use are perceived by family members is lacking in this body of literature (Adams, Bailey, Anderson, & Docherty, 2011). Further, although nurses believe that what they do is beneficial to family members in supporting their decision-making, nurses use strategies that might be harmful, such as giving incomplete information that leads to false hope, pushing families to make decisions, being blunt, encouraging family members to witness the suffering of the patient (Adams et al., 2011), and sharing personal opinions (Adams, Bailey, Gentry, et al., 2010). Without knowledge of what strategies family members find helpful or harmful and without training, nurses might rely only on intuition to guide them in these conversations (Docherty, Miles, & Brandon, 2007).

Evidence from the medical literature on communication at EOL indicates that having difficult conversations with family members is a skill that must be learned, not something that is guided by instinct (Back et al., 2009). Although some of the skills identified in the medical literature might be useful for nurses, because the role that nurses play in this process is different from that of physicians, it is important to identify

the specific strategies that are unique to the nurse and how family members respond to these nursing strategies. Understanding how family members respond to nursing strategies will contribute new knowledge for practice and intervention development.

## **1.2. Background**

### **1.2.1 Complexity of EOL Decision-Making Process in the ICU**

Intensive care units are designed to deal with acute life-threatening problems that require life support. These units are busy, rapidly changing, noisy, and intimidating to a person not familiar with the environment (Zomorodi & Lynn, 2010). Physicians usually rotate in and out of the unit, and nurses often work three twelve-hour shifts per week. The resulting inconsistency in health care professional presence is a barrier to good communication in the ICU

Although many ICU patients have reversible conditions, a large number of patients who die in ICUs have reached the end of a chronic fatal illness (Angus et al., 2004; Rady & Johnson, 2004). A recent two year study of patients who died in a tertiary hospital in the US demonstrated that of the 10,000 patients admitted to the hospital, 252 died, and 196 (65%) of those hospital deaths occurred in the ICU (Rady & Johnson, 2004). When a patient in the ICU has a chronic fatal illness, the focus of care might shift from extending life to supporting a peaceful death. This shift in focus involves decisions to limit or withdraw life supportive care and to instead focus on aggressively treating

pain and symptoms. These so called end-of-life decisions might include how and when to withdraw ventilators, vasopressors, antibiotics, and enteral or parenteral nutrition and hydration. These decisions are by nature complex, emotionally charged, and compounded by factors related to the ICU environment, the nature of the patient's illness, and the attitudes of the family and the health care professionals involved in the care of the patient. Because most ICU patients lack decision-making capacity (Delgado et al., 2009; Goold et al., 2000; Hiltunen et al., 1999; Smedira et al., 1990), proxy or surrogate decision-makers, often family members, are called upon to make these difficult decisions.

## **1.2.2 Proxy Decision-Making**

### **1.2.2.1 Defining the proxy**

When a patient lacks decision-making capacity, a proxy or surrogate decision-maker is called upon to make the decision for that person. The proxy ideally should be someone who knows the patient's wishes. Usually the proxy is one or more family members, defined in this study as "those persons who are emotionally intimate or familiar with the patient" (S. Bailey, 2002, p. 484). Each state has laws defining who might take on the role of proxy or surrogate, (Lo & Steinbrook, 2004) also known as the legally authorized representative (LAR). If a patient has designated a health care power of attorney in an advance directive (AD), then the LAR is the person named in that

document. If there is no document, then each state has a hierarchy of who might serve in the role of the LAR (Berger, DeRenzo, & Schwartz, 2008; Lo & Steinbrook, 2004). Often the LAR is a spouse, child, partner, or sibling. Although the LAR is the official decision-maker, in many families, persons other than the LAR are included in the decision-making process. For example, a husband might name his wife as health care power of attorney, thus giving her the authority of LAR, but the adult children might be the ones who are most able to comprehend the medical information and might counsel the wife in the best decision. In some situations the LAR might live a great distance away and might give the informal decision-making power to relatives who are in closer proximity.

#### **1.2.2.2 How the decision is made**

The complex process of EOL decision-making involves interpreting the prognosis, deciding whether to use substituted judgment (the implicit or explicit wishes of the patient) or the principle of best interest (what is best for the patient) and balancing quality of life with burdens of treatment (L. Emanuel, Danis, Pearlman, & Singer, 1995; Winzelberg, Hanson, & Tulsky, 2005). Federal law, state laws, and bioethics recognize a process of hierarchical decision-making: (a) known wishes, expressed either verbally or written in a living will (b) substituted judgment, a surrogate's best understanding of what the patient would want based on the patient's expressed values and goals; and (c) best interests, a decision based on what is deemed to be in the patient's best interests

(Berger et al., 2008).

### **1.2.2.3 Advance directives**

#### *1.2.2.3.1 Definition of advance directives*

Advance directives (AD) are legal documents created to preserve the principle of patient autonomy and the right to refuse life-prolonging treatment (Winzelberg, Hanson, et al., 2005). These documents allow people to indicate their wishes in advance of potential loss of capacity for decision-making. The advance directive consists of two documents, a living will and a health care power of attorney (HCPOA). The living will addresses the prolongation of life by use of artificial nutrition/hydration or support of respiration by a ventilator, and the HCPOA appoints one or more proxy decision makers. In 1991 the US Congress passed the Patient Self-Determination Act mandating that health care facilities receiving government funding inform patients of their right to complete these directives (Reams & Couture, 1994). Despite this mandate, many people do not complete advance directives nor do they talk with their proxies or physicians about their EOL wishes (E. J. Emanuel, Weinberg, Gonin, Hummel, & Emanuel, 1993; Teno et al., 1997).

#### *1.2.2.3.2 Limitations of advance directives*

Advance directives have several limitations. They are not widely used, they lack

flexibility, and they are not consistently interpreted. Results from the SUPPORT study indicated that only 20-25% of hospitalized patients had completed an advance directive (Teno et al., 1997); a recent retrospective cohort study of 284 deaths in a large teaching hospital demonstrated that only 22% of hospitalized patients who died had a written advance directive (Morrell, Brown, Qi, Drabiak, & Helft, 2008); and a study of 203 patients admitted from an ICU to a respiratory care unit with chronic critical illness after a tracheostomy showed that 22% had an HCPOA and 16% had a living will (Camhi et al., 2009). However, results from a recent national survey found that 71% of people who died had completed at least part of an advance directive (Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007), and a recent study of elderly people in nursing homes and in the community demonstrated an association between having completed a living will and dying outside of the hospital (Degenholtz, Rhee, & Arnold, 2004). Thus, it appears that the presence of an advance directive might prevent inappropriate hospitalization.

Although the presence of an advance directive should theoretically guide and direct care in the hospital, researchers have found that having an AD does not appear to improve decision-making or communication in hospitalized patients (Teno et al., 1997; Tulskey, 2005). Further, the presence of an advance directive does not reduce the probability of conflict between staff and family members of ICU patients who have life support withdrawn (Studdert et al., 2003). The reason that advance directives do not

have much impact on EOL care in hospitalized patients might stem from the flaws in the documents themselves as well as inconsistency in how they are used and interpreted.

Advance directives do not address a person's overall goals for care, including quality of life versus burdens of treatment, nor do they address the issues of burden to the family members who are making the decisions (Berger et al., 2008). Further, personal, family, or cultural variability in preferences for decision-making are often not captured in advance directives (Berger et al., 2008). These documents lack the ability to capture the underlying uncertainty, complexity, fluidity, unpredictability, and complexity of EOL decision-making in chronic fatal illness (Berger et al., 2008; Collins, Parks, & Winter, 2006; Lo & Steinbrook, 2004; Perkins, 2007).

The advance directive lacks the specificity and sensitivity needed to help surrogates make decisions based on substituted judgment (Berger et al., 2008; Sudore & Fried, 2010). Advance directives are completed in one moment in time and represent only a snapshot of what a person wants at the moment they are completing the document. Because a person's perspective might change over the course of an illness, what a person might have wanted early in the diagnosis might be radically different from what that person would want in the end stages (Collins et al., 2006). Advance directives do not allow for this fluidity.

Variations exist in how the advance directives are used and interpreted. Often

when a patient arrives in a hospital, the providers are unaware of the existence of an advance directive and do not have access to the document (Morrison, Olson, Mertz, & Meier, 1995; Perkins, 2007; Tulsky, 2005). Family members might misunderstand the meaning of the document, lack knowledge of patient's wishes, and might confuse their own wishes with that of the patient (Perkins, 2007). Further, some physicians are not willing to abide by what is written in the document, allowing the family to override it (Perkins, 2007). Some people execute a living will with the intent that it be used as a strict guideline to be followed by a single decision-maker, whereas others might see it as a fluid document, expect the surrogate to use his/her best judgment, and might want the decision-making to be shared among the family members and the health care professionals (Berger et al., 2008; Winzelberg, Hanson, et al., 2005). The advance directives commonly used do not indicate this variability.

Once a person loses the capacity to express his/her desires, the living will might be all the family has to go on to determine what the patient would want. However, the presence of a living will has been shown to have no effect on the ability of surrogates to predict what the patient would want (Shalowitz, Garrett-Mayer, & Wendler, 2006). Even with a living will and a full knowledge and understanding of what the patient would want, a family might find making this type of decision very difficult. The family might not agree with what the patient has previously stated, and carrying out the wishes might



lead to ethical conflict and guilt (S. Bailey, 2002). Further, the family might disagree with the providers on the intent of the living will, which might lead to interpersonal conflict.

Because of these limitations, advance directives have fallen short of expectations that they would improve EOL care. The Patient Self-Determination Act and the use of advance directives have not had an impact on communication or decision-making in hospitalized patients (Teno et al., 1997; Tulsky, 2005). Therefore, many experts in the field of palliative and EOL care have recommended that the focus needs to shift from completion of advance directives to interventions that improve communication and lead to compassionate EOL care (Teno, 2004; Tulsky, 2005; Winzelberg, Hanson, et al., 2005).

### **1.2.3 Trajectory of EOL Decision-Making in the ICU**

The decision to initiate life support, often made in an emergency situation, launches the patient and family onto a trajectory of aggressive care that will persist until either the patient recovers or a decision is made to withhold or withdraw life support (Gutierrez, 2010). The term “trajectory” is used in health sciences as a way of understanding life pathways characterized by varying levels of functioning (Clipp, Pavalko, & Elder, 1992). Within these trajectories, people experience life events, such as a stroke or heart attack, that affect the overall trajectory (Clipp et al., 1992). Although a stay in the ICU might be seen as a life event, it also has its own trajectory. When a patient has a poor prognosis for survival, a decision to withhold or withdraw life

support characterizes a trajectory of transition from curative to palliative care. These trajectories are marked by the time the patient spends in the ICU and by ICU events, such as a blood clot in the lungs, organ failure, or cardiac arrest, and are also influenced by the level of certainty that the physicians have that the patient is not likely to survive (Gutierrez, 2010).

In an ethnographic study of EOL decision-making in the ICU, Gutierrez (2010) identified four main trajectories of transition from curative to palliative care in the ICU (Gutierrez, 2010). The first trajectory is a trajectory of early certainty about the poor prognosis, with the physician(s) making a determination that the patient will not survive within the first 24 hours. This trajectory is rare because most physicians prefer to give the patient a chance to respond to treatment. The second is the trajectory of certainty within the first 72 hours. Physicians prefer to observe the patient's response to treatment over a period of 48-72 hours to identify trends before determining that the patient is not going to respond to treatment. The third trajectory is marked by a two week time period when typically a decision must be made whether or not to perform a tracheostomy. The fourth trajectory is a lingering trajectory, where the uncertainty about prognosis persists past two weeks, often in situations with an unclear diagnosis or etiology.

The more certain the physicians are about the prognosis, the earlier they initiate discussions about prognosis with family members (Gutierrez, 2010). Over this trajectory,

the condition of the patient might wax and wane. The members of the health care team and the family members might have different and changing perceptions of the condition of the patient and the patient's response to treatment. At some point, the family member and health care team communicate with each other about the prognosis. This communication about prognosis opens the door to discussions about EOL decisions.

Because of the inherent uncertainty in prognosticating, lack of training, and discomfort discussing death (Christakis & Iwashyna, 1998), physicians often do not approach family members about withdrawal or withholding of life support until they have exhausted all curative options and have a level of certainty that recovery is very unlikely or death is inevitable or imminent (Gutierrez, 2010). Consequently, many family members, who have been anticipating a cure (Counsell & Guin, 2002), are shocked when faced with a discussion about terminating life support and have difficulty making a decision. In addition to the shock, these family members might be asked to make a very difficult and emotionally charged decision with little time to process the information (Ahrens, Yancey, & Kollef, 2003). Family members faced with these difficult decisions need and want clear, honest information (Nelson, Puntillo, et al., 2010), yet both physicians and nurses, uncomfortable with the inherent uncertainty in prognosis, might avoid, hedge, and use euphemisms and jargon that lead to confusion and false hope (Baggs & Schmitt, 2000; Goold et al., 2000; Hov, Hedelin, & Athlin, 2007; Silen,

Svantesson, & Ahlstrom, 2008; Steinhauser et al., 2001).

### **1.2.4 Consequences of Decision-Making for Family Members**

When faced with EOL decisions, family members of patients dying in ICUs face significant burden. The experience of making EOL decisions for a loved one in an ICU is associated with a high prevalence of symptoms of acute stress, anxiety, depression, post-traumatic stress disorder (PTSD), and complicated grief in family members (Azoulay et al., 2005; Pochard et al., 2005). Because health care professionals are themselves uncertain about prognosis, they might give the family members vague or conflicting information (Goold et al., 2000). Further, when discussing difficult decisions, physicians and nurses might provide family members with technical information about the diagnosis and prognosis, offer several options, and expect the family to sort through the complex decisions (Frosch & Kaplan, 1999). When family members are faced with the decision to discontinue life support, they might be presented with several options involving complex problem solving, such as how to discontinue a ventilator and how to treat symptoms of air hunger, decisions for which most lay people are unprepared. For example, in a recent study of a family care conference an ICU fellow offered the family the following options:

We would probably leave him on the ventilator because ... taking him off might make him struggle a bit, or, what we could do is start him on a morphine

drip...Or we could just stop giving him the blood pressure medications...and then just not do anything with the ventilator (Adams, Bailey, Anderson, & Galanos, 2013).

Although most family members express a desire to be involved in EOL decisions, family members differ in the way they make decisions and in their preferred level of control over these decisions (S. K. Johnson, Bautista, Hong, Weissfeld, & White, 2011; Winzelberg, Hanson, et al., 2005) and most are not prepared to engage in this level of complex problem solving (Frosch & Kaplan, 1999).

The uncertainty of EOL decision-making might lead to feelings of guilt, regret, anxiety, and depression in family members who might fear they are giving up too soon or that their loved one will experience pain (Abbott, Sago, Breen, Abernethy, & Tulsky, 2001; Azoulay et al., 2005; Kirchhoff et al., 2002; Steihauser et al., 2001, p. 204). In a qualitative study exploring the experience of family members making EOL decisions in an ICU, those who had participated in EOL decision-making within the prior three months expressed a sense of personal responsibility for their decision. One participant stated, "It's a lot like being on a jury in a murder trial, and you've got to determine whether this guy's going to go sit on death row...it's a horrible burden upon the juror" (Braun et al., 2008, p. 269). Another stated, "You're taking this person's life in your hands" (Braun et al., 2008, p. 269). In another qualitative study, authors likened the

family members' experience to being in a vortex, experiencing a cascade of events characterized by feelings of guilt and regret (Kirchhoff et al., 2002). The wife of one patient who had died 16 months earlier stated, "If I had paid a little bit more attention to what was being said...then perhaps there was something else that might have been done" (Kirchhoff et al., 2002). This type of uncertainty can leave family members with regret and self-doubt that can contribute to complicated grief, depression and PTSD.

### **1.2.5 Role of Nurses and Physicians in Facilitating EOL Decision-Making.**

Although the roles of physicians and nurses in the process of EOL decision-making in the ICU differ, they also overlap. The distinct role of physicians includes making a medical diagnosis, revealing the diagnosis and prognosis to the family, and determining appropriate medical treatment options. Because the physician is responsible for revealing the diagnosis and prognosis, a great deal of medical literature regarding EOL decision-making in acute care has focused on communication skills and procedures for communicating bad news (Barclay, Blackhall, & Tulskey, 2007; Clayton et al., 2008). Nurses' role includes the "alleviation of suffering through the diagnosis of human response and advocacy in the care of individuals and families" (ANA, 2010a, p. 1). Nurses provide information to family members, support family members in their decision-making, and advocate for family members and patients (Adams et al., 2011).

Although the scope of nursing practice does not prohibit nurses from discussing the prognosis and treatment options with family members, many ICU cultures have implicit rules that discourage nurses from doing so (Baggs et al., 2007; Calvin, Kite-Powell, & Hickey, 2007; Calvin, Lindy, & Clingon, 2009; Robichaux & Clark, 2006; Sorensen & Iedema, 2007). Despite such unwritten rules, many nurses do engage in discussions with family members about the prognosis, the likelihood of treatment being successful, and treatment options, including withdrawal of life support (Adams et al., 2011).

Although the medical literature provides strong evidence of the importance of and effectiveness of good communication skills when discussing sensitive issues with family members at EOL, the nursing literature does not provide evidence of what nursing strategies are most helpful to family members who are making EOL decisions.

A systematic review of the medical literature addressing communication with families at the EOL revealed four domains: content of communication, style of communication, responsibility for the decision, and barriers to effective communication (Adams, Bailey, Anderson, & Tulskey, 2012). A systematic review of the nursing literature on nursing roles in EOL decision-making in acute care revealed that nurses play one of three roles: advocate, information broker, and supporter (Adams et al., 2011). The information from these two literature reviews are synthesized below using the framework of the four domains of communication from the medical literature. This was

supplemented by adding what was found in the nursing literature about the roles nurses enact and strategies they use for each domain. Each domain includes a description of how my planned research will advance knowledge in that domain.

#### **1.2.5.1 Content of communication**

The medical literature provides evidence that the content of formal family meetings should include introductions, including the purpose of the meeting and foreshadowing; information about the patient's condition in lay terms; information about the role of the family in surrogate decision-making; discussion of the prognosis, including the prognosis for survival as well as for QOL and the inherent uncertainty of prognostication; discussions of dying and death; and a closing summation with plan for follow-up (Barton, Aldridge, Trimble, & Vidovic, 2005; Curtis et al., 2002; Engstrom & Soderberg, 2004; Evans et al., 2009; Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007; Wiegand, 2006b; Zier et al., 2008). Although several multicomponent interventions using these recommended techniques demonstrated positive outcomes for family members and/or patients (Campbell & Guzman, 2003, 2004; Lautrette et al., 2007; Lilly et al., 2000; Lilly, Sonna, Haley, & Massaro, 2003; Mosenthal & Murphy, 2006; Mosenthal et al., 2008), wide variation exists in the content of family meetings to deliver this information (Mallery, Hubbard, Moorhouse, Koller, & Eeles, 2011; White, Braddock, Berecknyei, & Curtis, 2007; White, Engelberg, Wenrich, Lo, & Curtis, 2010).



Because the scope of nursing practice does not include making a medical diagnosis (ANA, 2010a), nurses usually are not the first to discuss a prognosis with family members. Several studies indicate that family members prefer that information about the patient's prognosis come from the physician, whereas the nurse is expected to fill in the gaps in information and provide updates on the evolving condition of the patient (Gutierrez, 2010; Kirchhoff et al., 2002; Verhaeghe, van Zuuren, Defloor, Duijnste, & Grypdonck, 2007). Other studies have indicated a need for consistent information from the health care team (Carline et al., 2003; Nelson, Puntillo, et al., 2010). In a prospective pilot study a family member expressed this same need (Adams, Bailey, Gentry, et al., 2010). One exception was when the physician was not familiar with the patient, in which case the family member said, "And we depend more on the nurse and the nurse gives us more accurate information. And it's okay to be inconsistent then"(Adams, Bailey, Gentry, et al., 2010).

A little explored strategy that nurses use in palliative care, oncology, and mental health is self-disclosure, such as telling a person about one's hobbies or interests, as a way of building trust (Ashmore & Banks, 2001; Dowling, 2008; Gramling, 2004). Oncology and critical care patients have expressed that a reciprocal sharing of personal interests and hobbies made them feel closer and have more trust in their nurses (Dowling, 2008; Gramling, 2004). Physicians are traditionally taught not to self-disclose;

however, the medical literature reveals that physicians do often use self-disclosure in patient encounters (Beach, Roter, Larson, et al., 2004; Beach, Roter, Rubin, et al., 2004). Although self-disclosure might help to build relationships and model healthy behavior (D. S. Morse, McDaniel, Candib, & Beach, 2008), it might also be disruptive and inappropriate (McDaniel et al., 2007).

Another type of self-disclosure involves sharing about one's own past decisions as a way to support or perhaps influence decision-making. With the exception of one editorial describing the use of this technique in an attempt to help a family member make the decision to withdraw life support (Rousseau, 2009), the palliative care literature does not address the ethics of self-disclosure of one's own choices in the past. However, the ethics of self-disclosure has been explored in the field of genetic counseling. The conclusions from this field are that; although this type of self-disclosure might help to validate the person, normalize the process, and provide alternative perspectives; when discussing complex and ethically charged decision-making, sharing personal stories about similar experiences is risky, as it might unduly influence the family member and thereby undermine autonomy (Thomas, Veach, & Leroy, 2006). In addition, sharing personal stories might distract the family member from focusing on their own experience and might create confusion (Thomas et al., 2006). Neither the nursing nor the medical literature provide any data on the extent to which nurses and

physicians might use self-disclosure of personal experiences as a strategy to support or influence decision-making and how family members respond to this strategy.

When enacting the roles of information broker, supporter, and advocate nurses do give information to the family about the prognosis (Adams et al., 2011). Nurses might also use self-disclosure as a method of supporting decision-making, as was noted in a my pilot study where the wife of the patient expressed that she was upset by a nurse who had given her an unsolicited “personal opinion” (Adams, Bailey, Gentry, et al., 2010). The nursing literature provides minimal evidence of how family members perceive nurses as they enact these roles (Adams et al., 2011). This literature lacks details from family members about what specific communication strategies nurses use to complete such tasks as “fill in the gaps” and “provide updates on the evolving condition of the patient.” This literature does not provide evidence of whether and how nurses use self-disclosure in EOL discussions. Further, information about whether or not family members find these strategies helpful to their ability to make decisions that are consistent with the goals of the patients and to handle the stress of making these decisions is lacking. My study provides new information about how family members perceive the strategies nurses use as they enact their professional roles including how they perceive these strategies as helpful or unhelpful.

#### **1.2.5.2 Style of communication**

The medical literature identifies several key components of EOL communication with family members, including demonstrating empathy and respect (Barclay et al., 2007; Curtis et al., 2002; Curtis et al., 2005; Engstrom & Soderberg, 2004; Nelson, Puntillo, et al., 2010), fostering hope, providing support for family members, and assuring non-abandonment (Barton et al., 2005; Clayton, Butow, Arnold, & Tattersall, 2005; Clayton et al., 2008; Gutierrez, 2010; Heyland et al., 2003; Jacobowski, Girard, Mulder, & Ely, 2010; Stapleton, Engelberg, Wenrich, Goss, & Curtis, 2006; West, Engelberg, Wenrich, & Curtis, 2005; Wiegand, 2006a, 2006b). When physicians use techniques such as assessing needs, discussing patient wishes, listening, tailoring information, building rapport, being accessible, and using lay language, families are more satisfied (Abbott et al., 2001; Crichton, Coyne, Tate, Swigart, & Happ, 2008; Fineberg, Kawashima, & Asch, 2011; Gries, Curtis, Wall, & Engelberg, 2008; Lautrette et al., 2007; Selph, Shiang, Engelberg, Curtis, & White, 2008; Wiegand, 2006b). In several studies that used these techniques, positive patient outcomes were also demonstrated (Lilly et al., 2000; Lilly et al., 2003; Mosenthal et al., 2008).

The nursing literature also addresses the importance of good communication skills and fostering realistic hope as nurses enact the roles of information broker, supporter, and advocate (Adams et al., 2011). Nurses develop trusting relationships with family members and assess family members' needs (Puntillo & McAdam, 2006;

Thelen, 2005). The contact that nurses have with family members allows them to explore the family members' understanding of the patient's condition and the patient's preferences as well as the family's preference for involvement in the decision-making process. Further, the nurse can assess the family's readiness to talk about EOL decision-making (Murphy et al., 2001).

The literature provides evidence that nurses who are actively engaged in EOL decision-making provide information and help family members to see the "big picture" despite implicit rules discouraging such engagement (Adams et al., 2011). Some of the strategies these nurses used included encouraging the family to consider what the patient would want (Hsieh, Shannon, & Curtis, 2006), preparing the family for bad news (McMillen, 2008), helping family to understand the consequences of decisions (Hilden & Honkasalo, 2006; Liaschenko, O'Connor-Von, & Peden-McAlpine, 2009), and helping the family members to maintain realistic hope and reframe hope (Engstrom & Soderberg, 2007; Robichaux & Clark, 2006). Several authors have described nurses engaging in direct behaviors that might not be beneficial to family members, such as pushing families to make decisions (Calvin et al., 2007), providing personal opinions (Calvin et al., 2007), being very blunt (Robichaux & Clark, 2006), telling family members that the patient is dying (Calvin et al., 2009), encouraging family members to observe treatments so that the family can see that the patient is suffering (Robichaux & Clark, 2006), and

using prognostic tools to initiate EOL discussions with families (Weber, Courtney, & Benham-Hutchins, 2009). However, this literature does not describe how family members respond to these potentially harmful behaviors.

Other nurses use indirect strategies or avoid engaging in EOL discussions altogether (Calvin et al., 2007). Indirect strategies include dropping hints to family members (Calvin et al., 2009) and to physicians (McMillen, 2008) and timing EOL discussions to coincide with the schedule of the physicians thought to be more open to EOL discussions (Baggs et al., 2007). Some nurses use avoidance tactics, such as being vague and reluctant to give information to family members (Lind, Lorem, Nortvedt, & Hevroy, 2011), failing to advocate to the physician for the patient/family (Sorensen & Iedema, 2006), and providing facts without interpretation (Verhaeghe et al., 2007; Zaforteza, Gastaldo, de Pedro, Sanchez-Cuenca, & Lastra, 2005).

Although the literature provides ample studies of how nurses perceive they are involved in EOL decision-making and several studies describing what family members perceive that they need from health care professionals in general, what is lacking is literature that describes the family members' perceptions of the specific strategies that nurses use to support their decision-making and how family members respond to these strategies over the trajectory of the decision-making process in the ICU (Adams et al., 2011). Because nurses might often act on instinct when dealing with patients

transitioning from curative to palliative care (Docherty et al., 2007), the strategies they use might or might not be perceived as helpful by family members making EOL decisions. The studies described in this dissertation built on prior work by exploring in greater depth the specific strategies and behaviors that family members perceive nurses using and how family members respond to these strategies and behaviors. In-depth interviews of family members while they were making these decisions allowed a deeper understanding of family members' perceptions of and responses to specific nursing strategies over the trajectory of the decision-making process.

#### **1.2.5.3 Responsibility for decision-making**

The medical literature indicates inconsistency in the willingness of physicians to take responsibility for the decision-making process. Some take a paternalist approach (Kryworuchko, Stacey, Peterson, Heyland, & Graham, 2012; Winzelberg, Hanson, et al., 2005; Winzelberg, Patrick, Rhodes, & Deyo, 2005); some shift the responsibility to others, including the patient, the family member, and other physicians (Deep, Griffith, & Wilson, 2008; Gutierrez, 2010; N. Johnson, Cook, Giacomini, & Willms, 2000; Mallery et al., 2011; Norton & Bowers, 2001); and still others share the responsibility (Curtis et al., 2002). In addition, this literature indicates variability in what family members want, with a majority preferring a shared style of decision-making (Heyland et al., 2003; Mayer & Kossoff, 1999). Several studies have demonstrated that family members desire to hear

a physician recommendation (Gries et al., 2008; Vig et al., 2007; White, Evans, Bautista, Luce, & Lo, 2009). A recent study found that for value laden decisions, 55% wanted to make the final decision, 40% wanted to share the responsibility with the physician, and 5% wanted the physician to make the final decision; however, 90% wanted to hear a recommendation from a physician (S. K. Johnson et al., 2011).

The nursing literature indicates an evolution in the role of nurses in EOL decision-making and variability in how willing nurses are to share decision-making responsibility with physicians and family members (Adams et al., 2011). Some nurses avoid any discussion of decisions, instead deferring to the physician out of fear of overstepping their role and because involvement in EOL discussion can be emotionally draining (Calvin et al., 2007). However, through enacting the role of advocate, others might influence decisions by explaining the consequences of decisions, telling the family that the patient is dying, and encouraging the family to consider what the patient would want (Adams et al., 2011). Some nurses have reported actively giving recommendations to family members to withdraw life support (Calvin et al., 2007). The nursing literature does not provide adequate information about how family members respond to nursing advocacy. My pilot study revealed that a family member was very upset that a nurse gave a "personal opinion," however, the informant was unable to remember the details (Adams, Bailey, Gentry, et al., 2010). The family members in my pilot study also stated



several times that they valued hearing information from nurses that was congruent with information from physicians. This is consistent with the medical literature that indicates that family members want congruency of information from different sources (Zier et al., 2008). However, in my pilot study, the daughter-in-law was quick to point out that on evenings, nights, and weekends, when they perceived that the doctor on call knew less about the patient than the nurse knew, they appreciated the nurse giving them information that might be inconsistent with what the doctor said because they trusted the nurse more. This study allowed me to explore further how family members perceive the role of the nurse as advocate by exploring the difference between a professional recommendation and a personal opinion, how family members respond to nurses who give recommendations versus personal opinions, and how family members respond to nurses who give information that is different from the physician.

#### **1.2.5.4 Barriers**

The literature indicates the presence of many barriers to effective communication between health care providers and family members, including systems barriers, family member barriers, and physician barriers (Anselm et al., 2005; Nelson et al., 2006).

##### **1.2.5.4.1 Systems barriers**

Systems barriers faced by physicians include limited reimbursement for

palliative care, technological imperative of the ICU, lack of support for interdisciplinary communication and coordination, busy work schedules, lack of continuity of care, lack of sufficient space to meet with families, lack of palliative care services, difficulty locating an advance directive, and institutions that do not recognize EOL care as a priority (Anselm et al., 2005; Nelson et al., 2006). Nurses face similar systems barriers, as well as barriers unique to nursing, such as lack of a formal structure to express their assessments (Sorensen & Iedema, 2007), poor communication between nurses and physicians (Calvin et al., 2009; Kirchhoff et al., 2000), and unwritten rules that discourage nurses from engaging in EOL discussions (Baggs et al., 2007).

#### *1.2.5.4.2 Family member barriers*

The evidence in the medical and nursing literature indicates that family members might fail to understand the nature and seriousness of the patient's illness because of intra family turmoil (Breen, Abernathy, Abbott, & Tulsky, 2001; Studdert et al., 2003), cultural or language barriers (Barclay et al., 2007; Hancock et al., 2007; Studdert et al., 2003), or a failure of the health care professionals to adequately explain the situation (Barton et al., 2005; Todd, Van Rosendaal, Duregon, & Verhoef, 2005; Verhaeghe et al., 2007; Zaforteza et al., 2005). In addition, family members might not believe what they hear because of mistrust or conflicting information (Zier et al., 2008; Zier et al., 2009).

#### *1.2.5.4.3 Practitioner barriers*

Physician barriers include uncertainty about prognosis (Anselm et al., 2005), emotional difficulty of talking about death (Ahern, Doyle, Marquis, Lesk, & Skrobik, 2012; Barclay et al., 2007; Clayton et al., 2008; Kryworuchko et al., 2012), and lack of training and experience in EOL communication (Ahern et al., 2012; Hancock et al., 2007; Nelson et al., 2006; Siddiqui & Holley, 2011).

Nurses also struggle with uncertainty about prognosis (Calvin et al., 2007; Hov et al., 2007; Sorensen & Iedema, 2006; Thompson, McClement, & Daeninck, 2006) and lack of skills to engage in discussions with family members about EOL decisions (Bach, Ploeg, & Black, 2009; Briggs & Colvin, 2002; Kirchhoff et al., 2000; Murphy et al., 2001; Wise, 2004). In addition, many nurses express a belief that discussing EOL issues is outside the scope of their practice (Calvin et al., 2009; Hov et al., 2007; Kirchhoff et al., 2000; Lopez, 2009; McMillen, 2008; Reinke, Shannon, Engelberg, Young, & Curtis, 2010). Nurses who are uncomfortable discussing EOL decisions might avoid the topic altogether or even avoid caring for patients who might be facing EOL decisions (Calvin et al., 2007; Norton & Talerico, 2000). Because nurses lack training and skills in supporting family members during times of decision-making, they rely on instinct (Docherty et al., 2007). Thus, empirical evidence of what strategies are effective in supporting family members is needed so that nurses can guide their practice by knowledge of what works rather than practicing on instinct alone.

By gleaning information from family members about how they perceive and respond to nursing strategies, the role of the nurse in EOL decision-making can be more clearly delineated. As the role of the nurse becomes clearer to nurses and physicians, nurses can be better trained to enact their roles in ways that facilitate interdisciplinary communication as well as communication between health care practitioners and family members.

### **1.2.6 Conclusion**

Family members of patients dying in the ICU are faced with agonizing dilemmas, the consequences of which might haunt them for a lifetime (Anderson, Arnold, Angus, & Bryce, 2008; Auerbach et al., 2005; Azoulay et al., 2005; Curtis & Engelberg, 2006; Gries et al., 2010; Pochard et al., 2001; Pochard et al., 2005; Siegel, Hayes, Vanderwerker, Loeth, & Prigerson, 2008). Providing these family members with meaningful support and information is imperative. Nurses, by virtue of the time spent at the bedside and knowledge of patient and family needs, are in a unique position to support family members as they process the information they are receiving.

However, most of the studies of nursing literature in this area involve nurses' self-report (Adams et al., 2011), whereas the medical literature in this review includes multiple studies where physicians were examined interacting with family members (Adams et al., 2013; Aldridge & Barton, 2007; Crighton et al., 2008; Curtis et al., 2002;

Curtis et al., 2005; Deep et al., 2008; Fineberg et al., 2011; Gutierrez, 2010; Hsieh et al., 2006; Mallery et al., 2011; McDonagh et al., 2004; Selph et al., 2008; Stapleton et al., 2006; West et al., 2005; White, Braddock, et al., 2007; White, Engelberg, Wenrich, Lo, & Curtis, 2007; White et al., 2010). The literature on physician communication provides more descriptive evidence of the way physicians communicate with families and what families expect from physicians. In addition, several intervention studies indicate that the use of particular communication techniques, especially when used in a proactive and multidisciplinary fashion, is beneficial to patients and families (Campbell & Guzman, 2003, 2004; Lautrette et al., 2007; Lilly et al., 2000; Lilly et al., 2003; Mosenthal et al., 2008; Mosenthal et al., 2011; White, Braddock, et al., 2007). Studies also demonstrate that physicians can be taught these communication techniques (Fineberg, 2005; Kelley et al., 2012; Klaristenfeld, Harrington, & Miner, 2007; Lorin, Rho, Wisnivesky, & Nierman, 2006).

The nursing literature is less mature in its exploration of communication techniques at the EOL. Literature that describes the responses of family members to nursing communication strategies is lacking. In addition, interventions that specifically target nursing communication are lacking. My research has added to the body of literature by describing the responses of family members to nursing communication strategies and provides a jump off point for development of new ways to train nurses to

enact their roles in an effective manner.

### ***1.3 Purpose Statement and Aims***

The overall purpose of this dissertation is to understand the involvement of nurses in EOL decision-making, including the factors that influence nurses' willingness to advocate and how family members of critically ill patients who are likely to need complex EOL decision-making respond to the strategies that nurses use when engaging in EOL discussions. This purpose was accomplished by four overall aims, with each chapter representing one aim.

#### **1.3.1 Chapter 1 Aim**

Introduce the problem and significance

#### **1.3.2 Chapter 2 Aim**

Analyze and synthesize the literature on nursing roles and strategies in EOL decision-making in the ICU. This was accomplished by a systematic search of the literature followed by critique, and synthesis. Finally, recommendations were made for future directions (Adams et al., 2011).

#### **1.3.3 Chapter 3 Aim**

The first aim was to determine the feasibility of identifying an ICU patient who was likely to not survive the ICU stay; interview the family members, nurses, and physicians

involved in the care of the patient; and record family meetings. The purpose of the analysis was to describe the behavior of HCPs and responses of family members through the lens of Adaptive Leadership in a prospective case study of a patient transitioning from curative to palliative care (Adams, Bailey, Anderson, & Thygeson, in press).

### **1.3.4 Chapter 4 Aims**

#### **1.3.4.1 Chapter 4 Aim 1**

Describe the specific strategies that nurses use during the trajectory of the decision-making process in the ICU from the perspective of family members.

#### **1.3.4.2 Chapter 4 Aim 2**

Explore how family members perceive these strategies to be helpful or not helpful in their ability to make decisions on behalf of their loved one.

#### **1.3.4.3 Chapter 4 Aim 3**

Describe how these strategies might change over the trajectory of the decision-making process from the perspective of family members.

This dissertation was intended to analyze and synthesize what is known about the role of nurses in EOL decision-making in acute care and add new knowledge about how family members respond to nursing strategies so that nurses can be taught how to successfully facilitate EOL decision-making in the ICU setting. This study is the first to

follow family members prospectively and longitudinally in an ICU environment over the trajectory of EOL decision-making to explore how they perceive and respond to nursing strategies. The knowledge generated from this study has laid the foundation for future intervention work grounded in empirical findings of what strategies family members find beneficial to their ability to make decisions. Without such knowledge base, any intervention work aimed at improving family members' ability to make decisions runs the risk of being grounded in strategies that are not effective. Future intervention work will pave the way for incorporating these beneficial strategies as standards for nursing practice in this setting so that nurses will be able to guide their practice based on empirical evidence of what family members find helpful rather than being guided solely by intuition and instinct. The ultimate goal of this work is to help family members make decisions that are consistent with their values and goals for EOL care.



## **2. Literature Review**

### **2.1 Abstract**

(Adams et al., 2011)

The objective of this review was to analyze the literature concerning nurses' roles and strategies in EOL decision-making in acute care environments, synthesize the findings, and identify implications for future research. We conducted searches in CINAHL and PubMed, using a broad range of terms to include nurses' role, family member, surrogate, hospital care, end-of-life care, terminal care, withholding or withdrawal, prognosis, quality of life, decision-making, judgment, resuscitation orders, and patient participation. The 44 articles retained for review had quantitative and qualitative designs and represented ten countries. These articles were entered into a matrix to facilitate examining patterns, themes, and relationships across studies. Three nursing roles emerged from the synthesis of the literature: Information broker, supporter, and advocate, each with a set of strategies nurses use to enact the roles. Empirical evidence linking these nursing roles and strategies to patient and family member outcomes is lacking. How nursing communication activities are received by patients and families and whether these activities are effective in helping them to make decisions that are consistent with their goals are areas for future research.

Key Words: Acute care, end-of-life, decision-making, and role of nurse, withdrawal of care, withholding of care.

## **2.2 Introduction**

End-of-life (EOL) decision-making in acute care is complex, involving difficult decisions, such as whether to initiate or discontinue life-support, place a feeding tube or a tracheostomy, or initiate cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest. Because of the severity of illness and the nature of treatments, acutely ill patients often lack decision-making capacity, which puts the family members in the role of decision-maker (Delgado et al., 2009; Goold et al., 2000; Stroud, 2002; Thelen, 2005). One of the biggest challenges to EOL decision-making is prognostic uncertainty and determining when to initiate EOL discussions with family members (Christakis & Iwashyna, 1998; Oberle & Hughes, 2001). Nurses and physicians express fear of removing all hope, making the wrong decision, or giving up too soon (Hov et al., 2007; Liaschenko et al., 2009; Silen et al., 2008). Further, it is difficult emotionally for both family members and health care professionals to give up on curative care (Christakis & Iwashyna, 1998; Harris, 2002; Hiltunen et al., 1999). Unfortunately, health care professionals feel inadequately trained to determine when and how to initiate these discussions (Christakis & Iwashyna, 1998; Espinosa, Young, Symes, Haile, & Walsh, 2010; Murphy et al., 2001). Thus, EOL discussions may begin when the physician

decides to discuss a do not resuscitate (DNR) order, which often this takes place when the prognosis is poor (Westphal & McKee, 2009) and the patient is no longer able to participate. A study of intensive care unit (ICU) cultures revealed that the decision to insert a percutaneous endoscopic gastrostomy (PEG) tube and a tracheostomy often triggered EOL discussions, which, on some units, did not occur until the patient was imminently dying (Baggs et al., 2007). Another factor that makes EOL decision-making difficult is the lack of clarity in the roles of the different health care professionals. Although it is the role of the physician to make a diagnosis and to communicate the diagnosis to the patient or family member, other health care professionals, such as nurses, social workers, and chaplains, have legitimate roles in the EOL decision-making process.

The SUPPORT (1995) study was a landmark study that set the stage for contemporary research about EOL decision-making. Phase I of the SUPPORT (1995) study, a multi-site investigation into the delivery of EOL care, demonstrated that poor communication about EOL issues resulted in many patients receiving life-sustaining care that they did not want and experiencing moderate to severe pain at the end of life. Phase II of the SUPPORT study (1995) involved a comprehensive approach to improve the medical decision-making and outcomes for critically ill patients, including a nurse intervention. In addition to gathering information from patients and/or surrogates, the

SUPPORT nurses provided both educational and emotional support to the patients and family members (Murphy et al., 2001). Although the intervention arm did not improve the study outcomes of decreasing the length of time to obtain a DNR order, length of stay in ICU, and resource utilization (SUPPORT, 1995), subsequent analyses of narrative data from this study demonstrated that nurses played a significant role in supporting the patients and families and guiding them toward a readiness to withhold or withdraw care (Hiltunen et al., 1999; Murphy et al., 2001).

Nurses are at the bedside during the dying process; they spend entire shifts with patients and families, they develop trusting relationships, and they are competent to assess patient and family needs (Puntillo & McAdam, 2006; Thelen, 2005). Nurses gain a unique perspective that allows them to become aware when a patient is not responding to treatment (Hanna, 2004; McMillen, 2008). This perspective places nurses in a position to facilitate EOL decision-making. A systematic understanding of what roles nurses enact and what strategies they use in EOL decision-making is necessary to ensure that decisions made are consistent with the patient's and family's goals of care.

## **2.3 Aims**

To better understand how to improve the process of EOL decision-making we reviewed the literature to describe how nurses are engaging in EOL decision-making with family members of acutely ill hospitalized patients, including the roles that nurses

enact and the strategies that they use to enact these roles, as well as the outcomes for patients and family members. The results provide a foundation to improve that process. The purpose of this research review, therefore, is to synthesize what is known about the roles nurses enact, the strategies they use to enact these roles, and how patients and family members respond to these strategies in EOL decision-making in acute care settings and to identify questions for significant future research. The findings of the literature review are organized around the three nursing roles that emerged from the review: Information broker, supporter, and advocate, followed by descriptions of the strategies that nurses use to enact these roles. We present the existing evidence of the outcomes of nurses' engagement in these roles with families and offer recommendations to inform future research.

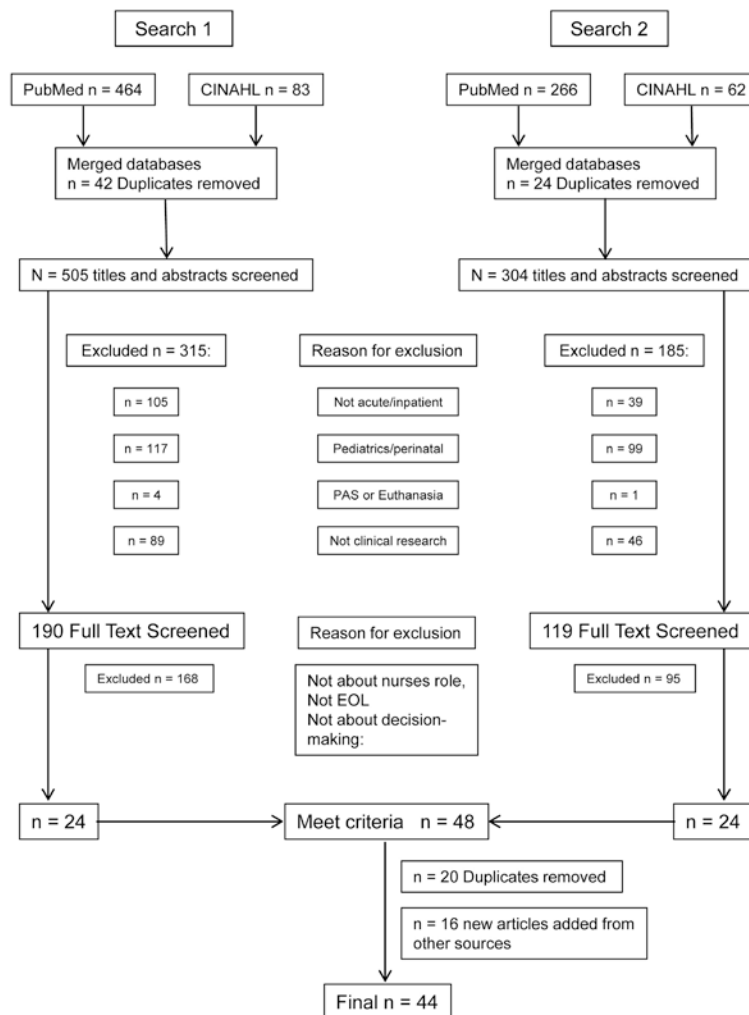
## ***2.4 Review Methodology***

This review of the literature covers a 15-year period from 1996 to 2011, to capture literature published following the SUPPORT (1995) study, a seminal work on this topic. We searched both PubMed and CINAHL using two sets of search terms. Search 1 terms were: nurses' role or nursing role or role of nurse PLUS families or family member or surrogate PLUS acute care or hospital care PLUS palliative care or end of life care or end-of-life care or terminal care or withholding or withdrawal or prognosis or quality of life. Search 2 terms were: nurses' role or nursing role or role of nurse PLUS families or

family member or surrogate PLUS acute care or hospital care PLUS decision making or judgment or resuscitation orders or patient participation. Searches were limited to the English language.

As summarized in the flow chart (Figure 1), for the search of each database, after removing duplicates, we reviewed the abstracts and titles for relevance and removed any that were pediatric or perinatal, outpatient/nursing home/or emergency room, not research (i.e. commentaries, case reports, editorials, position papers, and scholarly discussions), or were specifically about physician assisted suicide (PAS) or euthanasia. Those that remained were scrutinized in more detail by scanning the entire article. We removed any articles that were not relevant to the role of the staff nurse in EOL decision-making, excluding articles that discussed EOL care but not decision-making, those that discussed only moral distress of nurses, those that discussed the role of the physician or other health care provider but not that of the nurse, and other articles that discussed nurses' involvement in decision-making but were not EOL. We also excluded articles that did not address decision-making with the family members or surrogates. Although there are some differences in acuity of care and the level of technology between intensive care and acute care hospital units, the findings in studies of nurses' involvement in EOL decision-making in these environments were similar enough that we decided to include all studies of inpatient, acute care settings that addressed how

nurses are involved in EOL decision-making. At the end of this search process we had a total of 28 articles. We then reviewed the bibliographies of all of the retrieved articles using a snowballing technique that returned 16 additional articles for the review. See Figure 1.



**Figure 1: Flow Diagram**

Forty-four articles identified as meeting our criteria for inclusion were abstracted into a matrix for review and synthesis. We read each article thoroughly and systematically abstracted its content into a matrix (Garrard, 2007) with 11 headings: journal identification, purpose, variables, methodological design, sample design, number of subjects, analysis, validity and reliability, results, significance, and limitations. The matrix helped us examine the literature for patterns and themes across studies as well as relationships among studies. Using an inductive approach we analyzed the content of the findings and grouped them into four mutually exclusive categories. The designs of the articles were as follows: 32 qualitative, 7 quantitative descriptive correlational, two literature review, and three mixed methods design. Although 10 countries were represented only one was multinational (Latour, Fulbrook, & Albarran, 2009). The healthcare professionals who participated in the studies were mainly nurses; however, several of the studies were multidisciplinary including physicians (Baggs et al., 2007; Hsieh et al., 2006; Kennard et al., 1996; Reckling, 1997; Sorensen & Iedema, 2007; Viney, 1996) as well as social workers, chaplains, pharmacists, ethicists, and respiratory therapists (Baggs et al., 2007; Reckling, 1997). Six studies included the perspective of family members (Fox-Wasylyshyn, El-Masri, & Williamson, 2005; Fry & Warren, 2007; Kennard et al., 1996; Limerick, 2007; Lind et al., 2011;



Verhaeghe et al., 2007). Table 1 summarizes the study designs, setting, number of participants, participant characteristics, and results.

Table 1: Summary of Results

Author	Research Design	Setting/sample	Themes
Bach et al., 2009	Grounded theory	2 Critical care units in teaching hospital; 14 nurses; Canada (Ontario); 14 Nurses	SUPPORTER: Be present with families and listen. ADVOCATE: Help family to understand the implications of decisions, question physicians, speak up and give opinions at family meetings, help family think about what patient would want. Initiate discussion with physicians, explain things to family in lay terms, give honest information without taking away hope
Baggs et al., 2004	Literature Review	ICU; US	INFORMATION BROKER: Nurse as information broker and mediator OUTCOMES: Decrease costs and LOS and improved communication with multidisciplinary/collaborative interventions.
Baggs et al, 2007	Ethnographic	ICU; 34 case studies; US	ADVOCATE: Nurses timed EOL discussions for when a physician was on rotation who was seen as open to discussing EOL issues.
Barthow et al, 2009	Qualitative Descriptive	Tertiary cancer center; 21 nurses; New Zealand	INFORMATION BROKER: Provide and clarify information. SUPPORTER: Coaching, facilitating, offering choices. ADVOCATE: Help clarify goals and help family to understand ramifications of decisions.

Author	Research Design	Setting/sample	Themes
Bushinski. & Cummings, 2007	Qualitative" "appreciative inquiry" (Hammond).	Outpatient Palliative Care and a MICU; 8 nurses; US (Minnesota)	INFORMATION BROKER: Interpret what physician said. Arrange for family meetings. SUPPORTER: build trust, acknowledge emotions, explore statements, pause, allow time, be present recognize cues of readiness to talk, support, sit close and make eye contact, turn off phone and beeper, don't look at watch. rephrase, explore emotions. ADVOCATE: Ask leading questions.
Calvin et al. 2007	Qualitative Descriptive	Neuro ICU ;12 nurses; US	INFORMATION BROKER: Translate medical terms. Suggest and set up care conferences SUPPORTER: listen, maintain close connection with family, reassure. ADVOCATE: Elicit values, thoughts, and understandings from families, push family to make decisions at times, try to get MD to see big picture. "If she's not getting better, not waking up, then that's a sign that her brain is not functioning...and that should tell you that you need to take mom home and you need to love her and make those last days of her life more comfortable than being poked or prodded." p147
Calvin et al, 2009	Qualitative descriptive	CVICU; 19 nurses; US	ADVOCATE: Acknowledge physician authority, walk a fine line. Try to prepare family member, try to tell families without really telling them. Some would tell family even at risk of being reprimanded SUPPORTER: Promote family presence.
Engstrom & Soderberg, 2007	Qualitative: Focus groups	ICU; 24 nurses; Sweden	SUPPORTER: Nurses felt it was important to maintain hope and not give false hope Balance hope with realism. Hope for good death. ADVOCATE: Difficulty being honest when given conflicting info from physician. and when doing treatments nurse disagrees with.

Author	Research Design	Setting/sample	Themes
Espinosa et al, 2010	Descriptive phenomenological	ICU; 18 nurses; US	INFORMATION BROKER: Tell family members what they need to ask the physician. SUPPORTER: Build a trusting relationship with families.
Fox-Wasylyshyn et al, 2005	Descriptive Correlational	ICU; 29 family members; Canada	INFORMATION BROKER: Explain equipment. ADVOCATE: Explain prognosis.
Frank, R, 2009	Literature Review	Acute care and hospice settings; 9 articles; UK	INFORMATION BROKER: communicate honestly SUPPORTER: Allow patient time to make decision, support patient, recommendations of how nurses should enact their roles: engage in process with patient and physician, develop trusting relationship based on power sharing. ADVOCATE: Be assertive.
Fry & Warren, 2007	Phenomenology	ICU; 15 family members with varied ethnic and cultural backgrounds; US	SUPPORTER: Build trusting relationships, introduce self to family and explain equipment, demonstrate openness and willingness to talk. ADVOCATE: give honest information about how patient is responding to treatment. OUTCOMES: Developing trusting relationship allows family to feel that they can ask the nurse about the patient and trust that they will get the truth.
Harris, 2002	Grounded Theory	ICU; 9 nurses; UK	ADVOCATE: Advocated for care conferences
Haslett, 1998	Cross sectional explanatory descriptive	Acute care; 278 nurses (68% response rate); US	INFORMATION BROKER: Educate 68%, give information 58%. ADVOCATE: Advocate 81%. Only 7% assumed role of decision-maker (determining whether DNR was appropriate)
Heland, 2006	Qualitative Descriptive	ICU; 7 nurses; Australia	INFORMATION BROKER: Arrange for family meetings, and coordinate the meetings to get all the interested parties together. ADVOCATE: Explain the patient's condition to the family.

Author	Research Design	Setting/sample	Themes
Hilden & Honkasalo, 2006	Qualitative Interview	Acute, long-term, and home settings; 17 Nurses; Finland	INFORMATION BROKER: Provide information to the physician SUPPORTER: Provide emotional and existential support. ADVOCATE: Clarify information given by the physician by presenting it in a way that they can understand in lay terms. Help family understand the pros and cons of decisions. Lead the family and help them to see reality.
Hilden et al., 2004	Descriptive: questionnaire	All areas of care; 408 Nurses (51% response rate); Finland	ADVOCATE: 95% nurses felt it was their responsibility to talk to MD about a patient's LW if it was not being respected. 50% reported that they participated in DNR discussions with families when patient unable to communicate.
Hiltunen, E. F. et al, 1999	Narrative content analysis	5 hospitals; 23 nurse facilitators; US	SUPPORTER: "Midwife-one who understands the process unfolding and can be present with the family" pg. 132. Skill, patience, being present and sharing the experience with the family.
Ho et al., 2005	Survey	ICU, NICU, peds; 611 nurses; New Zealand	ADVOCATE: 78% of participants said they were "actively involved" in EOL decisions. 42-54% actively discussed EOL issues with patient or family. Actively involved defined as "active discussion with patients, families, or physicians in the decisions to withdraw life support or withhold cardiopulmonary resuscitation."
Hov et al., 2007	Qualitative: phenomenology	ICU; 14 nurses; Norway	SUPPORTER: Presence, see changes, holistic. ADVOCATE: Interpret what is going on with the patient and give their interpretation to the physicians "using different strategies" (these strategies not described). Help physician understand the suffering. Go to physician meetings and express their opinions

Author	Research Design	Setting/sample	Themes
Hsieh et al., 2006	Qualitative Content Analysis	ICU; 51 family meetings; US	ADVOCATE: Actively participate in family meeting. Relate to family what patient said before becoming unconscious. (very eloquent description of what patient wanted given by a nurse in a family meeting). Ask what pt. would want.
Jezewski & Finnell, 1998	Grounded Theory	Acute oncology settings; 21 nurses; US (New York)	INFORMATION BROKER: Be a third party to mediate among family members or between family and providers. Tell the physician what patient's wishes are. SUPPORTER: Be sensitive to family members' emotions. Listen, caring, assess emotional readiness. ADVOCATE: Help patient and family understand what DNR means. Be sure they are informed and support their decisions.
Kennard et al., 1996	Descriptive	Acute care; 1427 patients/surrogates, 696 nurses; 5 settings; US	INFORMATION BROKER: 95% reported that they gave information to the medical team about patient's medical status ADVOCATE: On day three 67% had no knowledge of their patient's preferences. 53% reported not advocating for patient preferences. 17% discussed prognosis with patients, 32% offered recommendations to the family or patient. 58% discussed options and educated about the treatments. OUTCOMES: 50% of patients or surrogates thought conversations with nurses were ""very much" or "quite a bit" helpful in their decision-making. 25% felt that nurses preferences had "quite a bit" or "very much" influence on their decision.

Author	Research Design	Setting/sample	Themes
Kirchhoff et al., 2000	Cross sectional qualitative descriptive	ICU; 21 nurses; US	SUPPORTER: Introduce the nurse coming in on next shift, show confidence in that nurse, facilitate shift change, show you care. Allow time to accept, facilitate, allow family to participate in care, make time and space for family rituals. ADVOCATE: Nurses believed it is physician's responsibility to give family information on prognosis initially. Fear of taking away hope, do not like to see families being given false hope. Families "look to nurse for 'real' answer." pg. 39.
Latour et al., 2009	Descriptive Correlational using survey	ICU; 62 nurses; UK, Netherlands, Italy, Norway, Sweden	ADVOCATE: 75% reported active involvement in decision. 39% reported being asked to participate by MD. 64% said they had initiated discussions w MD, 52% said they were not actively involved in discussions with physician colleagues.
Liaschenko et al., 2009	Qualitative: Focus Group	ICU; 27 nurses; US	INFORMATION BROKER: "Nurses are nodal points for exchange of information" pg. 227 Nurses obtain info from physicians, families and synthesize the info to develop a comprehensive picture of what is happening. SUPPORTER: Supporting journey. Build trust. ADVOCATE: Helped families see the "big picture," including QOL and continued deterioration. Tell families about consequences of interventions. "what are the chances of improving their quality of life." OUTCOMES: One nurse expressed a belief that they can have a significant impact on the outcomes and the need to be sure they are advocating for the patient.

Author	Research Design	Setting/sample	Themes
Limerick, 2007	Grounded theory	ICU; 4 hospitals in a system, 17 surrogate decision-makers; US (Texas)	INFORMATION BROKER: provide information SUPPORTER: Support, caring, sensitive, build trusting relationships. ADVOCATE: Help family member to understand what is happening with the patient and recognize futility. OUTCOMES: Help move family along in the decision-making process by helping to build trust and help family member to understand the futility of the situation.
Lind et al., 2011	Grounded theory	ICU; 3 University hospitals , one district hospital, 27 Family members; Norway	INFORMATION BROKER: Nurse communicated about everyday issues not about prognosis or decision-making. Nurses were vague and reluctant to give information. Some reported that the nurse did give information and was clear. Those were the families who reported shared decision-making. Nurses rarely involved in family meetings, nurses did not answer questions. OUTCOMES: Shared decision-making with increased involvement of nurse seemed to improve family members understanding of prognosis and they were more prepared to cope with death.
McMillen, 2008	Grounded Theory	ICU; 8 nurses; UK	INFORMATION BROKER: Provide medical team with information about families' viewpoint and about clinical status of patient. SUPPORTER: Support the family; prepare them for the bad news, find out what is important to them, how they see the situation. Help family with practical needs. Also attend to families' practical needs. ADVOCATE: Drop hints to physician. Question physician.

Author	Research Design	Setting/sample	Themes
Murphy et al., 2001	Content analysis	5 hospitals; 20 nurses; US	<p>INFORMATION BROKER: Educate about the disease process. Facilitate communication between family and staff.</p> <p>SUPPORTER: Presence, listening, empathy, explaining, clarifying, storytelling, and life review, assessing readiness. ADVOCATE: Discuss prognosis with family members and expected outcomes of treatment.</p> <p>OUTCOMES: Nurses expressed sense that families were burdened by being offered futile care.</p>
Reckling, 1997	Multiple Case Study.	ICU; 16 family members , 29 health care professionals including 15 Nurses; US	<p>ADVOCATE: Nurses did not participate in the initial discussions about withdrawal but did talk to families once the physician had brought it up. Of the 15 nurses observed, only 3 took a strong advocate role, the other 12 were either moderate advocate or neutral.</p>
Robichaux & Clark, 2006	Qualitative: Narrative analysis	ICU; 21 nurses; US	<p>INFORMATION BROKER: educate, consult other services, such as requesting an ethics consult</p> <p>SUPPORTER: establish trust, assess when is the right time to initiate discussions.</p> <p>ADVOCATE: Advocate, speak up for patient even if it risks being reprimanded. One nurse spoke in front of family when physician was not being honest. One refused to carry out orders that were against patients expressed wishes. Help family to reframe their hope. Speaking to family on patient's behalf. Help family to understand the situation, e.g.. ventilator does not help a person feel better. Show family what it is like (let them see suctioning, decubiti, etc.). One nurse told a mother, "we're torturing him." p 487.</p>



Author	Research Design	Setting/sample	Themes
Scherer et al., 2006	Descriptive Correlational using survey	ICU; 210 nurses (21% response rate); US	ADVOCATE: 96% had helped inform patients or families of condition and treatment options. 98% counseled patients or families about AD, 85% initiated discussion of AD.
Silen et al, 2008	Qualitative content analysis	Dialysis units and nephrology wards; 13 nurses; Sweden	SUPPORTER: support physicians, be available for patients and physicians to talk to. ADVOCATE: Question physicians while at the same time recognizing the difficulty of the physicians' position. INFORMATION BROKER: convey information, e.g.. tell physician about patient wishes and any questions that families have raised. OUTCOMES: Belief that the family may be burdened by the responsibility and feel they "held the patient's life in their hands." p 168.
Sorensen & Iedema, 2006	Grounded Theory	ICU; 30 nurses; Australia	INFORMATION BROKER: Nurse feels caught between family and physician. Family wants to talk to physician, nurse asks physician to talk to family, physician says he/she has already talked to them SUPPORTER: Let family express their feelings, be sensitive to feelings. Establish a rapport, prepare families. ADVOCATE: Some of the nurses in study did not advocate for patient and did not give any professional opinion to the physician about the appropriateness of continuing aggressive care. Others talked to MD and told them of patient's preference to stop treatment. Nurse expressed putting in his/her "five cent's worth" at the family meeting. Nurses often left out of meetings. Importance of ongoing discussions of the plan of care and what the next steps would be if treatment doesn't work.

Author	Research Design	Setting/sample	Themes
Sorensen & Iedema, 2007	Ethnographic	ICU; Tertiary care hospital, 13 case studies, 15 family conferences, 29 focus groups with nurses, interviews with medical and nursing management; Australia (Sydney)	INFORMATION BROKER: provide information about patients' emotional and psychological status. Nurses contribute knowledge about psych and emotional issues to the team. What seemed to be missing was "a therapeutic engagement" of the nurse with the patient and family. ADVOCATE: Nurses see suffering but may be reluctant to speak frankly to family.
Thompson et al., 2006	Grounded theory	Acute care; 2 hospitals, 10 nurses; Canada	INFORMATION BROKER: empower by giving information, mediate, clarify information given by MD. ADVOCATE: Assess what patient/family understand, educate about disease process and possible outcomes, communicate honestly, cue patient/family and physician about signs of poor prognosis, push for DNR order from MD, encourage family to consider what pt. would want. OUTCOMES: "Smooth lane change" leads to collaborative care plan, appropriate level of care, ability to address symptoms, psychological support. Failure to do so leads to false hope for patient/family, moral distress for nurses, inability for nurse to be honest with patient/family, family may question why patient isn't getting better and become angry.

Author	Research Design	Setting/sample	Themes
Todd et al., 2005	Exploratory mixed methods design	Acute care; 2 teaching hospitals, 17 Acute Care Nurses; Canada	ADVOCATE: Initiator, 76% used the term advocate. One nurse reported nurses argued with physician about a decision to place PEG where patient died soon after. Nurses don't always actively seek to be part of decision-making process. INFORMATION BROKER: educator, teacher, provided information and answered questions. Liaison with physician, mediator. Nurses encouraged patients to talk to their physician and ask questions. SUPPORTER: support provider.
Verhaeghe et al., 2007	Grounded theory	ICU; 1 University, 1 regional hospital, 22 family members; Belgium	INFORMATION BROKER: Family identifies the nurse who gives adequate information. Some nurses give information that leads to false hope For example, if the nurses says his BP is stable, family may interpret that as good, when really the patient is doing much worse. SUPPORTER: Caring, telling little details about daily care or patient. ADVOCATE: Inform family about how the patient's condition is progressing, are things "moving in the right direction." More than just facts, but interpretation of facts. OUTCOMES: Families may misinterpret facts as a good prognostic sign. The way the information is given to the family affects their ability to come to terms with the ICU experience and dying process.

Author	Research Design	Setting/sample	Themes
Viney, 1996	Phenomenology	ICU; 5 physicians 5 nurses; UK	INFORMATION BROKER: relay information between family and physicians. Speak to physician on behalf of family, "put in two pennyworth." SUPPORTER: empathy, prepare family for withdrawal. ADVOCATE: Game playing, indirectly influencing the physician. Not actively involved in the decision-making process
Weber et al., 2009	Grounded Theory	ICU; 3 ICUs in 1 hospital, 10 Physicians 23 Nurses; US	ADVOCATE: Advocate to physicians and to family. Use results of prognostic tool to initiate EOL discussions with physician and family.
Wise, 2004	Mixed methods	Acute Care; 3 hospitals, 16 nurses (Phase 1), 100 nurses (Phase 2); US (Florida)	ADVOCATE: Intervene with physician, explain things to family, help them see futility, start EOL discussions. Get help and advice from more confident or experienced nurses reported "standing up" to the physicians to advocate for patients.
Zaforteza et al., 2005	Qualitative	ICU; 14 observations, 6 nurse interviews; Spain	INFORMATION BROKER: Gave meaningless information, such as "he/she has had a good night," or "he/she has slept more or less." SUPPORTER: Nurses ignored family members, did not introduce themselves but focused on technical activities. Nurses did not try to establish a relationship with the families. ADVOCATE: Did not give any interpretations about how patient is doing

Author	Research Design	Setting/sample	Themes
Zomorodi & Lynn, 2010	Qualitative descriptive	ICU; 9 nurses; US	<p>INFORMATION BROKER: Ask physician to speak to the family. SUPPORTER: calm, flexible, communicate with others well, pain and symptom management. Nurse sets own opinion aside and allows family to make decision. When decision made to withdraw, nurse takes a step back to allow family time w patient. One nurse described allowing a family member to get into the bed and lay down beside a dying relative. ADVOCATE: When asked what would you do, answer "what do you think the patient would want." Talk to physician and be frank about assessment that care is futile and should change direction. Be assertive with physicians.</p>

## **2.5 Findings**

Synthesis of the reviewed literature revealed that nurses' role in EOL decision-making has evolved since the SUPPORT study (1995). Results of studies from 1996 to 2000 indicate that nurses were more indirect in their approach. A much-cited study by Viney et al. (1996) indicated that nurses perceived that they did not have a legitimate role in EOL decision-making. Some nurses reported use of game playing and indirect techniques with physicians to influence decisions (Viney, 1996). In this and other studies, nurses advocated for patients or family members by informing physicians of patients' expressed wishes and speaking to the physician on behalf of the family (Jezewski & Finnell, 1998; Kennard et al., 1996; Viney, 1996). Although there is evidence that some nurses continue to use indirect strategies, more recent studies demonstrate that many nurses now use more direct approaches, such as talking to physicians and family members about prognosis and implications of decisions. This review also revealed a paucity of evidence examining relationships between nurses' involvement in EOL decision-making and patient and family outcomes. From this review we found that nurses enact three roles in EOL decision-making: Information broker, supporter, and advocate. Each role is presented below with a discussion of the strategies nurses use to enact these roles (summarized in **Table 2**). Finally, we discuss the evidence of the effect that nurses' actions have on patient and family outcomes.

**Table 2: Summary of Roles, Strategies, and Outcomes**

Information Broker	Supporter	Advocate	Outcomes
<u>Information to Physicians</u> <ul style="list-style-type: none"> <li>• Patient and family preferences</li> <li>• Emotional readiness</li> <li>• Clinical condition of patient</li> </ul>	<u>Build Trust</u> <ul style="list-style-type: none"> <li>• Introduce self and oncoming nurse</li> <li>• Practical needs</li> <li>• Provide details about patient and daily care</li> <li>• Accept decisions</li> <li>• Explain equipment</li> <li>• Willing to talk</li> <li>• Rituals</li> <li>• Story-telling and life review</li> <li>• Help maintain hope</li> <li>• Prepare for bad news</li> <li>• Assess readiness</li> <li>• Negative: Ignore family and focus on technical details</li> </ul>	<u>Advocate to Physicians</u> <ul style="list-style-type: none"> <li>• Speak out in meetings</li> <li>• Question or coach</li> <li>• Plant seeds</li> <li>• Time discussions around physician seen as most open</li> </ul>	<u>Accept that Patient is Dying</u> <ul style="list-style-type: none"> <li>• Prepare</li> <li>• Help let go</li> </ul>

Information Broker	Supporter	Advocate	Outcomes
<u>Information to Family</u> <ul style="list-style-type: none"> <li>Educate about disease process</li> <li>Explain equipment</li> <li>Translate/interpret medical terms</li> <li>Clarify</li> <li>Educate</li> <li>Give information only without interpretation</li> <li>Provide meaningless information</li> </ul>	<u>Empathy</u> <ul style="list-style-type: none"> <li>Emotional support</li> <li>Acknowledge feelings</li> <li>Take time to listen</li> <li>Support physicians as well as family members</li> <li>Allow family time to process information</li> </ul>	<u>Advocate to Family</u> <ul style="list-style-type: none"> <li>Give clear information</li> <li>Interpret information</li> <li>Explore goals</li> <li>Explain implications of decisions</li> <li>Encourage to consider what patient would want</li> <li>Describe how patient is responding to treatment</li> <li>Explain prognosis</li> <li>Blunt at times</li> <li>Tell family patient is dying</li> <li>Sometimes vague and not involved</li> </ul>	<u>Make Better Decisions</u> <ul style="list-style-type: none"> <li>Get the truth from nurses</li> <li>Understanding of prognosis</li> <li>Trusting relationships, allowed family to ask more questions</li> <li>Move along in decision-making process</li> <li>Good death</li> <li>Fear that families carry burden of guilt</li> <li>Satisfaction with care</li> </ul>
<u>Mediate</u> <ul style="list-style-type: none"> <li>Coordinate family meetings</li> <li>Consult other disciplines</li> <li>Request ethics consult</li> <li>Facilitate communication between family and medical team</li> <li>Ask physician to speak to family</li> <li>Coach family in what to ask physicians</li> </ul>		<u>Extent of Nursing Advocacy:</u> <ul style="list-style-type: none"> <li>75% actively involved in EOL decisions</li> <li>42-54% discuss EOL decisions with patient or family members</li> </ul>	



### **2.5.1 Information Broker**

Nurses play an important role in facilitating communication between and among family members and between family members and the health care team (team). The strategies nurses use to enact this role are presented in three categories: Give information to physicians, give information to family members, and mediate.

#### **2.5.1.1 Give information to physicians**

In a literature review on the role of the interdisciplinary team in caring for dying patients in an ICU, Baggs et al. (2004) found that nurses were described as “information brokers” (p.532), a traditional role described by Viney (Viney, 1996) in which they relay information about the patients and families to physicians. Other studies describe nurses enacting this role by providing the team with information about the patient’s clinical status (Kennard et al., 1996; McMillen, 2008), about the patient’s and family’s emotional and psychological state (Sorensen & Iedema, 2007), and about patients’ and families’ expressed wishes (McMillen, 2008; Silen et al., 2008). Liaschenko (2009) extended this role further by describing nurses as “nodal points for exchange of information” (p.227) with nurses obtaining information from many sources, synthesizing that information, and using it to develop a holistic assessment. This holistic or “big picture” (p. 224) assessment allows nurses to expand their role from information broker to supporter and advocate. These studies demonstrate that nurses are an important source of information

to aid physicians in EOL decision-making.

#### **2.5.1.2 Give information to family members.**

These strategies range from explaining equipment (Fox-Wasylyshyn et al., 2005), the patient's condition, and diagnosis to the family (Fox-Wasylyshyn et al., 2005; Murphy et al., 2001; Reckling, 1997; Robichaux & Clark, 2006; Todd et al., 2005); translating medical information into lay terms (Bushinski & Cummings, 2007; Calvin et al., 2007; Liaschenko et al., 2009); and explaining, educating, and clarifying meanings of terms, such as DNR (Bach et al., 2009; Barthow, Moss, McKinlay, McCullough, & Wise, 2009; Jezewski & Finnell, 1998). In one study, family members reported that when nurses gave just technical information without synthesizing and interpreting the meaning of that information, they might have instilled false hope (Verhaeghe et al., 2007). For example, in a neurological ICU, a family member shared that when a nurse told her that the patient's intracranial pressure (ICP) had come down, she was elated, believing that this was a sign that the patient was getting better. In reality this patient's condition was steadily declining, and the ICP reading was insignificant to the prognosis (Verhaeghe et al., 2007). Nurses who feel inadequately prepared to give information to family members may give them meaningless information, such as "he/she has had a good night," (Zaforteza et al., 2005) (p.140). Family members, in a study of their experience in an ICU, reported that the nurses were often vague, reporting everyday

details but not information about prognosis (Lind et al., 2011).

#### **2.5.1.3 Mediate**

In EOL situations, nurses enact the role of information broker by bringing people together to exchange information directly and facilitating communication among family members as well as between the family and the team. Nurses coordinate family meetings (Bushinski & Cummings, 2007; Calvin et al., 2007; Harris, 2002; Heland, 2006) where they may act as a third party to mediate (Jezewski & Finnell, 1998). Nurses may also request the presence of other disciplines, including chaplains or social workers, to mediate EOL discussions (Fry & Warren, 2007; Robichaux & Clark, 2006). Further, nurses may request that a physician speak to a family (Zomorodi & Lynn, 2010) or prompt a family member in what questions to ask the physician (Espinosa et al., 2010).

The evidence is strong that nurses play an active role in brokering information among family members and the health care team to facilitate communication about EOL decision-making. Overall these studies provided rich data describing the role that nurses play and the strategies they use in gathering and delivering information between family members and the medical team. Further, these findings provide evidence that the role of nurses in informing families is important and valued by nurses and by family members. However, one study included prospective observations (Zaforteza et al., 2005) and no study followed the participants longitudinally over a period of hospitalization to

determine if the information needs changed. A prospective longitudinal study would provide data about changing needs of families and how nurses respond to these needs.

### **2.5.2 Supporter**

Nurses enact the supporter role in EOL care by building trusting relationships with family members as they navigate the EOL decision-making process and by demonstrating empathy for patients, family members, and physicians.

#### **2.5.2.1 Build trust.**

Nurses provide support to families by taking time to develop trusting relationships. Family members reported that they trusted nurses who introduced themselves to the family, explained equipment, and were willing to talk (Fry & Warren, 2007). Nurses also identified the importance of establishing a rapport with families (Espinosa et al., 2010; Robichaux & Clark, 2006; Sorensen & Iedema, 2006). Nurses reported taking time to introduce the family to the oncoming shift nurse to show confidence in that nurse and facilitate the shift change (Kirchhoff et al., 2000). In this same study nurses reported allowing family members to take part in daily care and important rituals as a way of supporting the family (Kirchhoff et al., 2000). Other ways that nurses supported family members included finding out what is important to them, storytelling, life review, assessing readiness (Murphy et al., 2001), helping with practical needs (McMillen, 2008), helping them to maintain a sense of hope (Engstrom &

Soderberg, 2007), accepting their decisions (Jezewski & Finnell, 1998; Zomorodi & Lynn, 2010), and preparing them for bad news (McMillen, 2008).

#### **2.5.2.2 Empathy**

The literature is replete with examples of nurses enacting the role of supporter to family members of patients at the EOL through the use of empathy, using strategies such as trying to understand how the family members see the situation (McMillen, 2008), being present (Bach et al., 2009; Hiltunen et al., 1999; Hov et al., 2007; Murphy et al., 2001), taking time to listen, allowing the family time to process the information given (Bach et al., 2009; Frank, 2009; Hiltunen et al., 1999; Zomorodi & Lynn, 2010), and acknowledging feelings (Bushinski & Cummings, 2007; Limerick, 2007; Murphy et al., 2001; Viney, 1996). In one study nurses expressed a desire to support their physician colleagues by being “someone physicians can talk to” (p. 165), so that the physicians would not feel alone in the decision-making (Silen et al., 2008, p. 165).

Most of these studies were descriptive in nature and focused on the perspective of nurses and/or physicians and their perception of the role of nurses in EOL decision-making. Few included the perspective of the family members. In addition, most of the data were retrospective in nature, gathered from interviews, focus groups, or analyses of narratives where nurses described their own perception of their involvement and how families responded to this involvement, without including input from the family.

The literature provides evidence that nurses enact the role of supporter by use of many strategies to build trust and demonstrate empathy during the end of life period and that family members value this support, but the evidence of whether or not family members find this support helpful in the decision-making process is lacking.

Prospective studies that include the perspective of family members and nurses along with observations of interactions would provide evidence of the support that nurses are actually giving and how family members respond to that support.

### **2.5.3 Advocate**

Understanding about nurses' role as patient advocates at the EOL has evolved from indirect to active. The enactment of the advocate role may take the form of speaking to the medical team on the behalf of the patient or family as well as speaking to the family on behalf of the patient. One strategy that nurses use in both situations is to challenge the status quo. The expectation of family members and health care professionals in acute care is often one of cure with a tendency to pursue aggressive treatments that may be futile. In an attempt to advocate for their patients, nurses often find themselves in a position of challenging physicians and family members to consider changing the direction of care from curative to palliative.

#### **2.5.3.1 Advocate to physicians**

"A voice to speak up" (p. 504) was a theme that emerged from a grounded

theory study of nursing roles in EOL decision-making in the ICU (Bach et al., 2009, p. 504). In this and other studies nurses reported several modes of advocating, including going directly to the physician to report the expressed wishes of the family and questioning physicians about the plan of care (Bach et al., 2009; Silen et al., 2008). In another grounded theory study of nurses' roles in withdrawal of life sustaining treatment nurses described a more indirect mode of dropping hints or "planting the seed" (p. 254) to physicians that it may be time to change from curative to palliative care (McMillen, 2008). In other studies nurses have described coaching physicians (Zomorodi & Lynn, 2010) and timing EOL discussions to coincide with the schedule of a physician most likely to be open to EOL discussions (Baggs et al., 2007).

Some of the studies described a more assertive nursing role with nurses reporting pushing physicians to change the direction of care (Thompson et al., 2006), using results of prognostic tools to discuss the patient's prognosis with the physician (Weber et al., 2009), and arguing with physicians about the plan of care (Todd et al., 2005). In a study of expert nurses in critical care, a nurse described challenging a physician in front of the patient when the nurse perceived that the physician was not being honest with the patient; another nurse refused to carry out orders that were against the patient's expressed wishes (Robichaux & Clark, 2006).

### **2.5.3.2 Advocate to family**

The literature provides evidence that nurses advocate to families on behalf of patients about EOL decision-making. Nurses reported gently informing family members that their loved one was dying (Wise, 2004). Nurses helped family members to clarify the goals of care, challenging them to consider what the patient would have wanted (Bach et al., 2009; Robichaux & Clark, 2006) and explaining the implications of decisions (Barthow et al., 2009; Liaschenko et al., 2009). Nurses facilitated decision-making by presenting a realistic picture of what was happening, coaching the family members to make decisions that were consistent with their goals, (Barthow et al., 2009; Robichaux & Clark, 2006) and helping them to accept the inevitability of death (Bach et al., 2009).

One nurse emphasized the importance of explaining the implications of the diagnosis, stating “they may not have agreed...if they’d known all that” (Bach et al., 2009, p. 506) (p. 506). Nurses recognize that when a patient goes on life support, the result may be to prolong the dying process. In a study of EOL communication in the ICU, two nurses eloquently described the dilemma in which family members find themselves when patients opt for aggressive treatment that they may not comprehend (Liaschenko et al., 2009). The first nurse in this study described why some patients change their mind about intubation when in distress. “Because they are scared...They reverse their decision because the doctors ask them without communicating the whole



picture” (p. 227). The second nurse described her conversation with a patient thusly, “I said, ‘he’s asking you if you want to go on life support or if you want medication to keep you comfortable so you’re not scared [while dying]’ When I clarified this for the patient he chose option 2” (p. 227).

In the study by Robichaux and Clark (2006), expert nurses described taking a very assertive role in the EOL decision-making process with families. One nurse explained to a daughter that the ventilator was not helping her mother with end stage COPD to feel better or breathe easier; explaining that, in fact it was difficult to be on a ventilator. This daughter did eventually agree to withdraw the ventilator, and the patient died peacefully (2006). Other nurses in this study had the family members participate in daily care, such as suctioning and turning to allow the family member to see the decubiti, in an attempt to show the family member possible physical discomfort that the patient was experiencing. One nurse told a family member, “we’re torturing him” (p. 487).

Liaschenko, et al. (2009) found that nurses synthesized information to obtain a holistic view and gently challenged family members to consider the consequences of continued aggressive care. Nurses used the fact that patients were not responding to treatment or were continuing to deteriorate to facilitate having these discussions. In a study of the phenomenon of transition from curative to palliative care, nurses described

cueing the families about changes in the patient's condition that may indicate deterioration and a need to change course (Thompson et al., 2006).

Family meetings provided a forum for nurses to advocate for patients and family members. Nurses described speaking out in family meetings by expressing their opinions and the wants and needs of patients and family members, listening, and clarifying information (Bach et al., 2009). Hsieh et al. (2006) found that nurses were present in 41 of 50 family meetings that were recorded, and some nurses were actively involved. One nurse spoke eloquently explaining to the family members the expressed wishes of a patient not to be intubated, his agreement for a trial of a few days, and his wish to be taken off the ventilator after that time; this meeting took place six weeks after the patient's expressed wishes (Hsieh et al., 2006). Another nurse asked a family, "If he could sit up right now, what would he say to you. Would he say he wants to go on with all this? Would he say, stop, that's enough?" (p. 301)? Although Sorensen and Iedema (2006) found that nurses were not routinely included in family meetings and were not privy to what physicians had told the family, one nurse expressed that when attending a family meeting he/she would "put in my five cents' worth...at the end of it" (p. 191).

Interviews with family members of patients who died in ICUs revealed that family members had expectations that nurses would enact the role of advocate by providing meaningful information about patient prognosis (Fox-Wasylyshyn et al.,

2005). In other studies family members expected nurses to give honest information about how the patient's condition was progressing as well as an interpretation of that information (Fry & Warren, 2007; Verhaeghe et al., 2007). The participants in the study by Verhaeghe (2007) reported that nurses sometimes gave them only facts without interpretation, which lead to confusion and misunderstanding. Surrogates of patients who had died after withdrawal of life support in an ICU reported that nurses provided information to them about the condition of the patient and helped them to understand futility (Limerick, 2007). One study of family members revealed that nurses often were not present in family meetings, gave vague information, and did not answer questions directly; however, participants in this same study identified some nurses who were more forthright and gave clear information (Lind et al., 2011).

#### **2.5.3.3 Extent of nursing advocacy**

Estimates varied about the extent to which nurses are currently enacting an advocate role in EOL decision-making. Kennard et al. (1996) found that nurses advocated for their patients only 53% of the time, whereas Ho, English, and Bell (2005) found that 78% of ICU nurses were actively involved in EOL decision-making, and 42-54% actively discussed EOL decisions with the patient or family. In a study of ICU and oncology nurses' involvement in DNR orders, 81% reported taking on the role of patient advocate, and seven percent reported taking on the role of decision-maker (Haslett,

1998). A survey of ICU nurses' attitudes about EOL decision-making revealed that 95% believed that nurses need to respect patient's wishes, 98% would talk to a physician if a patient's wishes are violated, 96% would help inform the patient/family of the condition and treatment options, 98% counseled the patient/family about Advance Directives (AD), and 85% initiated discussion of ADs (Scherer, Jezewski, Graves, Wu, & Bu, 2006). In a study of ICU nurses' attitudes about withdrawing treatment, 75% of nurses reported they were actively involved and 64% said they had initiated discussions with the physician (Latour et al., 2009).

The findings from studies utilizing qualitative designs indicate that nurses perceive that they are challenging physicians and family members to see the big picture, consider the patient's wishes, consider the implications of decisions, and consider changing the direction of care from curative to palliative. The findings also demonstrate that family members have the expectation that nurses should be actively involved in the decision-making process by providing prognostic information and that nurses do not consistently do so. Evidence from quantitative studies about the level of nursing advocacy in EOL decision-making is sparse and provides conflicting results.

All but one (Baggs et al., 2007) of the above studies about the role of advocate were retrospective and none included observations of what nurses were actually doing and how these activities affected the decision-making process over time. A prospective,

longitudinal study combining interviews with observations would allow a comparison of nurses' reports of advocating with observations of these strategies. In addition, these data would describe whether and how decisions are altered by physicians and family members when nurses take an active role to advocate for a change in the direction of care from curative to palliative.

#### **2.5.4 Patient and Family Outcomes**

Nurses recognize their potential effect on EOL decision-making (Liaschenko et al., 2009), yet few studies addressed this effect. Although there is little empirical evidence of the effect nurses have on patient and family outcomes, the literature suggests that the roles and strategies nurses enact do affect the family members' ability to accept that the patient is dying and do affect the overall decision-making process. In a literature review Frank (2009) asserted that, through their roles in facilitating communication and allowing patients to remain in control, nurses can increase the likelihood of a good death.

##### **2.5.4.1 Accept that patient is dying**

Several qualitative studies indicated that nurses believe that the strategies they use help family members accept that a patient is dying by bringing families to "readiness" (Murphy et al., 2001), "enabling coming to terms," and "helping to let go" (Bach et al., 2009). Increased involvement of nurses in shared decision-making helped

family members in one study to understand and accept the prognosis and to prepare for and cope with death (Lind et al., 2011). In a study of family members of patients suffering from traumatic coma the participants expressed that the way they received information affected their hope and that when they received incomplete information or just facts, they were likely to misinterpret the information and have unrealistic hope (Verhaeghe et al., 2007).

#### **2.5.4.2 Making better decisions**

To make decisions, family members need to understand the condition of the patient and the options available; this necessitates receiving clear and truthful information. Studies of perceived needs of family members demonstrate that when family members developed trusting relationships with nurses, they could ask nurses questions, trust that they would get the truth, had a better understanding of the prognosis, and were more prepared (Fry & Warren, 2007; Lind et al., 2011). In addition, one study showed that when family members' needs were met, they were more satisfied with the care (Fox-Wasylyshyn et al., 2005). A grounded theory study of EOL decision-making revealed that family members' relationships with the nurses helped to move them along in the decision-making process (Limerick, 2007).

Studies of nurses demonstrate that nurses believe that what they do is important in preparing the family (Liaschenko et al., 2009) and moving the family along in the

process of decision-making (Hiltunen et al., 1999). Nurses also express that when there is a smooth transition from curative to palliative care, they are better able to manage pain and symptoms (Thompson et al., 2006). Some nurses expressed a fear that involving family members in EOL decision-making would lead to a sense of burden or guilt on the part of the family member (Murphy et al., 2001; Silen et al., 2008). One nurse expressed his/her concern that family members may feel like they “held the patient’s life in their hands” (Silen et al., 2008, p. 168) (p. 168). This sense of burden could affect a family member’s ability to make EOL decisions.

Evidence from studies of family members suggests that family members find nurses’ involvement to be sometimes beneficial and at other times harmful, such as when nurses give information without interpretation leading to false hope. In an analysis of data from the SUPPORT (1995) study researchers found that over half of the subjects reported that nurses’ involvement was helpful (Kennard et al., 1996). With the exception of two (Fox-Wasylyshyn et al., 2005; Kennard et al., 1996), the studies of family members or surrogates were qualitative and contained thick descriptions of family members’ experiences with nurses. The two quantitative studies used measurement tools that were developed based on information from nurses rather than information from the family members. The data suggest that family members may benefit from nurses’ taking an active role in providing meaningful information about

patient prognosis.

Nurses believe that families benefit from the strategies they use to enact the roles of information broker, supporter, and advocate, although some fear that family members carry a heavy burden of decision-making. In addition, families have reported that they found some of the strategies used by nurses to be helpful, especially when family members develop trusting relationships with nurses, receive adequate truthful information, and engage in shared decision-making. There is, however, no empirical link between specific nursing roles and strategies and outcomes for the family members of patients in acute care at the end of life. Further, there is a lack of evidence to explain how and why the roles that nurses enact are important to patients and family members.

## ***2.6 Discussion***

Since the findings of the SUPPORT study were reported in 1995, there has been a focus in the literature on improving communication that facilitates decision-making between physicians and patients/families at the end of life, with little focus on the role of nurses in EOL decision-making processes (Thelen, 2005). In those studies where nurses and physicians collaborated about EOL decision-making, positive outcomes, such as decrease in LOS, were achieved (Ahrens et al., 2003; Lilly et al., 2000; Lilly et al., 2003). Yet these studies were few, lacked experimental control and internal validity, and did not adequately describe the nurses' role, nor did they attempt to measure family



member outcomes.

The literature describing how nurses are involved in EOL decision-making can be summarized by the enactment of three nursing roles. First, as information brokers, nurses provide information about the patient and family to the health care team, provide information to the family about the patient, and coordinate EOL discussions. Secondly, as supporters, nurses provide an important source of emotional support to family members as they process the information they are given and attempt to make decisions. These forms of support include building trust and empathy. Thirdly, and most importantly, whereas earlier literature indicated that nurses were involved in an indirect manner, recent literature indicates that nurses are more actively engaged as advocates in EOL decision-making with both physicians and family members, challenging the status quo and helping all of the parties to see the big picture. Further, the literature suggests that when nurses are actively engaged with family members by interpreting and explaining to them what is happening and explaining prognoses, family members are more satisfied and able to move forward in their acceptance and decision-making.

### **2.6.1 Overview of Strength of Evidence**

The literature regarding nurses' involvement in EOL decision-making is based mainly on qualitative designs and provides rich data with thick descriptions of the experiences of nurses and family members in acute care end of life situations. Most of

the authors provided evidence of qualitative rigor, specifically confirmability through use of audit trails, dependability through use of multiple investigators in coding and analysis, credibility through use of search for disconfirming evidence and triangulation of data, and transferability through rich descriptions of findings. Four qualitative studies did not address or demonstrate qualitative rigor (Bushinski & Cummings, 2007; Hilden & Honkasalo, 2006; Thompson et al., 2006; Wise, 2004). Two studies mentioned methods of maintaining rigor, such as credibility, confirmability, auditability, but did not describe how this was done; both of these studies demonstrated transferability through rich descriptions (Heland, 2006; Murphy et al., 2001).

Seven quantitative studies described the level of involvement of nurses in EOL decision-making and the expectations of involvement by nurses and family members. Four of these studies provided no psychometrics for the instruments used (Hilden, Louhiala, Honkasalo, & Palo, 2004; Ho et al., 2005; Kennard et al., 1996; Latour et al., 2009), and three did not address the content validity of the instruments (Hilden et al., 2004; Ho et al., 2005; Kennard et al., 1996). In their study of family members' perceptions of nurses' role, Fox-Wasylyshyn et al. (2005) established content validity from nurses rather than from the family members, who were the stakeholders. The content validity ideally should have come from the literature or from qualitative research of family members. The study by Scherer et al. [52] had only a 21% return rate leaving the findings

vulnerable to selection bias. Overall the findings from the quantitative studies lacked validity.

The literature suggests that what nurses do is helpful to patients and families; there is limited empirical evidence, however, to demonstrate the unique and important role nurses have in EOL decision-making. Further, there is little evidence that patients and family members who have experienced an actively involved nurse will fare better than those who did not, as well as lack of a clear definition of what it means for a nurse to be actively involved in EOL decision-making.

### **2.6.2 Implications for Nursing Education, Practice, and Research**

As the global population ages and technology permits prolongation of life, dealing with dying patients and their families is likely to become a more frequent experience for all nurses, especially those in acute care environments. Nurses need guidance in enacting their roles in EOL decision-making so that they can alleviate suffering and ensure that EOL needs and goals for their patients and family members are being met. These nursing strategies should be guided by empirical evidence. Knowledge of what strategies nurses use to enact their roles, and what strategies are beneficial to patients and family members will guide nursing education, practice, and research. Understanding how nurses engage in this process is essential to the development of interventions to improve the strategies that nurses use in EOL decision-

making.

Prospective, longitudinal, and case oriented studies that identify how nurses engage in the EOL decision-making process, how the engagement changes with the needs of the family over the time of the hospitalization, and to explore the effect that nursing interventions have on patient and family member outcomes, are needed. Such studies would provide a systematic understanding of the strategies that nurses use and how and why family members respond to these strategies. In addition, strong quantitative studies that build on the rich descriptions in the existing literature to develop valid and reliable tools are needed to measure the extent to which nurses are enacting roles, the strategies they use, and the patient and family member outcomes. This would pave the way for larger scale quantitative studies and provide ways to assess any randomized controlled trials. With the knowledge generated from these studies, interventions could be developed that target areas identified as important to the family members and most likely to improve their well-being. This knowledge would allow for spreading expert nursing practices to all nurses in a systematic fashion, helping family members make decisions that are consistent with their values and goals for EOL care, and reducing the amount of psychological distress of family members who make EOL decisions in acute care environments.

## **2.7 Conclusions**

This review highlights the important role of nurses in EOL decision-making. Although nurses believe that their involvement is beneficial to patients and family members, this review reinforces the need for empirical evidence of these benefits at the end of life, especially as it relates to the well-being and coping of family members who are making difficult decisions about a loved one in an acute care environment. Better understanding of how nurses enact their roles in EOL care could improve the overall quality of communication in EOL care and help more patients and families make decisions that are consistent with their values and goals for EOL care.

## **3. Finding Your Way through EOL Challenges in the ICU Using Adaptive Leadership**

### **3.1 Abstract**

(Adams et al., in press)

#### **3.1.1 Objective**

Using the Adaptive Leadership framework, we describe behaviors that providers used while interacting with family members facing the challenges of recognizing that their loved one was dying in the ICU.

#### **3.1.2 Research Methodology**

In this prospective pilot case study, we selected 1 ICU patient with end-stage illness who lacked decision-making capacity. Participants included 4 family members, 1 nurse, and 2 physicians. The PI observed and recorded 3 family conferences and conducted one in-depth interview with the family. Three members of the research team independently coded the transcripts using *a priori* codes to describe the adaptive leadership behaviors that providers used to facilitate the family's adaptive work, met to compare and discuss the codes, and resolved all discrepancies.

#### **3.1.3 Results**

We identified behaviors used by nurses and physicians that facilitated the family's ability to adapt to the impending death of a loved one. Examples of these behaviors

include defining the adaptive challenges for families and foreshadowing a poor prognosis.

### **3.1.4 Conclusions**

Nurse and physician Adaptive Leadership behaviors can facilitate the transition from curative to palliative care by helping family members do the adaptive work of letting go. Further research is warranted to create knowledge for providers to help family members adapt.

## **3.2 Background**

Family members of patients for whom life support is withdrawn in the intensive care unit (ICU) face tremendous burden during the process of transitioning from curative to palliative care (Kirchhoff et al., 2002; McAdam & Puntillo, 2009; Pochard et al., 2001). During this transition family members are asked to make difficult decisions that involve adapting to the new reality that their loved one will not survive. Health care professionals (HCP) are in a position to facilitate this adaptation. However, because of prognostic uncertainty and discomfort talking about death, many HCPs avoid having end-of-life (EOL) discussions with family members and may inadvertently give the family misleading, conflicting, and ambiguous information (Barclay et al., 2007; Lind et al., 2011), which may lead to disparate understanding of the prognosis (Lind et al., 2011) and conflict between the HCPs and family members (Abbott et al., 2001; Breen et al.,

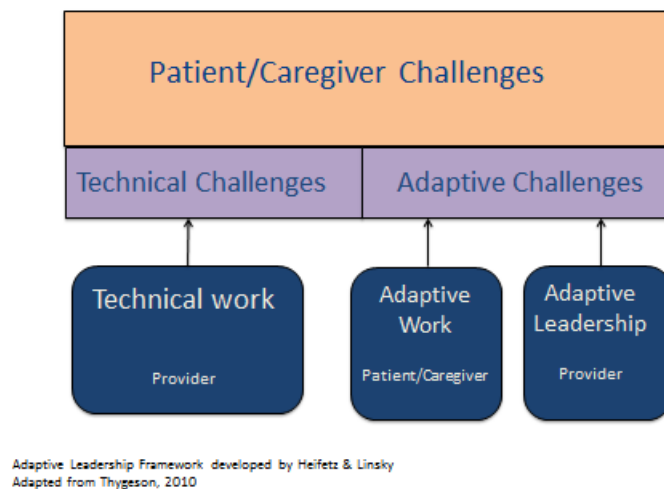
2001). Guidelines for palliative care in the ICU are based on the concept of patient/family centered care and shared decision-making (Davidson et al., 2007; Truog et al., 2008) requiring a shared understanding of the prognosis and the patient's goals among the HCPs and family members so that the best decision can be made for the patient (Crighton et al., 2008). To achieve this ideal, HCPs need tools to facilitate their communication with family members.

Adaptive Leadership (AL) is an organizational management framework based on complexity science (Thygeson, Morrissey, & Ulstad, 2010) where-in individuals and organizations are viewed as complex adaptive systems, responding to changes in their environment by adapting through self-organization (D. E. Bailey, Jr., et al., 2012; Cilliers, 1998). This framework describes two types of challenges, technical and adaptive (Heifetz, Grashow, & Linsky, 2009). Technical challenges are fairly straightforward and amenable to technical solutions, whereas adaptive challenges require the stakeholder change their attitudes, thoughts, and behaviors (Heifetz et al., 2009). Addressing an adaptive problem with a technical solution is a common mistake (Heifetz et al., 2009). This framework has recently been applied to the health care context to propose HCP behaviors that mobilize and support patients and family members as they face and adapt to changes (D. E. Bailey, Jr., et al., 2012; Thygeson et al., 2010).

The AL framework (see **Figure 2**) proposes that people with health problems face



both technical and adaptive challenges (Heifetz et al., 2009; Thygeson et al., 2010). An example of a technical challenge is surgery for appendicitis. Adaptive challenges are more complex and require the stakeholder to do the work of adapting; examples include dealing with a chronic illness, deciding between two treatment regimens, and facing loss (Thygeson, 2013; Thygeson et al., 2010). Adaptive work (AW) involves recognizing that technical solutions alone are not sufficient to address the challenges and requires changing attitudes, behaviors, and beliefs (Heifetz et al., 2009; Thygeson et al., 2010). Consequently, people often avoid or resist doing AW (Thygeson, 2013; Thygeson et al., 2010). The HCP can facilitate AW through AL, helping the stakeholder gain skills and capacities for change.



**Figure 2: Adaptive Leadership Framework**

Withdrawal of life support in the ICU involves both technical and adaptive challenges. Medical management of symptoms is an example of a technical challenge. The adaptive challenges involve recognizing that the prognosis is poor, identifying the patient's goals, and making decisions based on those goals. The AL framework provides a useful lens to identify HCP behaviors that are effective in facilitating the family members' ability to do the AW needed to make EOL decisions. Health care provider behavior can promote AW, inhibit it, or have a neutral effect. Adaptive Leadership is conceptualized as a set of behaviors that leaders (HCPs) manifest to facilitate AW. Consequently we have focused in this study on identifying and describing HCP behaviors that appear to facilitate AW, rather than on behaviors that may discourage or inhibit AW

### **3.3 Methods**

#### **3.3.1 Purpose**

The purpose of this study was to describe the behavior of HCPs and responses of family members through the lens of AL in a prospective case study of a patient transitioning from curative to palliative care.

#### **3.3.2 Ethical Approval**

Prior to data collection, the principal investigator (PI) obtained approval from the institutional review board and informed consent from each participant. Design

We chose a single prospective case study design to achieve our purpose. Case study involves in-depth examination of an integrated system; which in this case was the patient identified at high risk of dying, the family members, and the HCPs involved in the decision to withdraw life support. Case studies may be used either to understand an individual case or to illustrate an issue and answer a research question (Stake, 1995). In this study, the case was used to describe the communication between health care providers and family members as they navigated the decision to withdraw life support. We then applied the framework of AL to the analysis of this case to illustrate the behaviors of HCPs and family members as they navigated the transition from curative to palliative care. The data collected included observation of ICU daily rounds, observation and audio recording of three family conferences, and an interview with the family members. The case study design provided in-depth, contextual information about the relationships among the nurses, physicians, and family members, adding to the understanding of the complex dynamics of these discussions (Eisenhardt, 1989; Gerring, 2007).

### **3.3.3 Setting and Sample**

With the support of the medical and nursing leadership of the unit, the PI entered the medical intensive care unit in a Southeastern tertiary teaching hospital and attended daily multi-disciplinary rounds. She used criterion sampling to select a patient

for whom complex decision-making was likely but for whom discussions about withdrawal or withholding of life support had not yet occurred. The PI included the family members and health care professionals who were involved in the care of the patient and who had attended one or more of the family meetings in the sampling procedure.

### **3.3.4 Data Collection**

The data were collected in July of 2010. The PI collected demographic data from the participants and observed and audio-recorded three HCP-family meetings, which were held to discuss goals of care and withdrawal or withholding of life support. The PI then interviewed the family members together after the third family meeting, using narrative style, beginning with an open-ended question, "Tell me about how your family member came to be in the ICU, " followed by questions exploring the experience of the family members with their interactions with HCPs. This audio-recorded interview lasted 35 minutes and took place in a private room adjacent to the ICU. The data were de-identified to assure the privacy of the participants.

The PI visited the ICU for five to six hours daily for five consecutive days from the point at which the patient was identified until his death. Field notes, consisting of descriptions of the physical space, the participants, ICU activity, objects, acts, events, time, goals, and feelings (Crabtree & Miller, 1999), were recorded during and after each

family conference, attending rounds, observing the unit environment, and after the interview.

### **3.3.5 Data Analysis**

The overall goal of the analysis was to describe the behavior of HCPs and family members through the lens of AL as the patient transitioned from curative to palliative care. The digitally recorded interviews were transcribed (Bloomberg & Volpe, 2008) by a transcriptionist and accuracy verified by the PI by comparing the transcription to the recorded interview (Sandelowski, 1995). Transcribed interviews, field notes, and other text data were stored in an electronic database; ATLAS.ti qualitative data analysis software system (Silver & Lewins, 2009) was used to aid in coding, organizing, and managing the data.

Data were analyzed using deductive content analysis (Hsieh & Shannon, 2005). Although the data were collected using a narrative approach, the authors chose to use a directed approach to the analysis with the goal of extending and validating (Hsieh & Shannon, 2005) the AL framework. *A priori* codes were developed from the AL literature, and identified from a taxonomy of AL behaviors in health care developed by one of the physician authors (MT). The PI worked with MT to expand this taxonomy to reflect the AL behaviors and AW specific to EOL communication in the ICU, based on existing literature on communication between HCPs and families in the ICU and her

experience and expertise. Additional codes were added to the taxonomy during data analysis. New codes were discussed among the research team members before adding them to the codebook.

The data were examined in clusters with codes applied to each cluster (Graneheim & Lundman, 2004). Once the initial coding was completed, the coded text was arranged into categories and subcategories based on how they were related (Hsieh & Shannon, 2005). During analysis, the PI recorded memos to clarify coding decisions (Sandelowski, 1995) and to bracket assumptions (Hsieh & Shannon, 2005). Consultation with experts (co-authors) in the emerging field of AL in health care facilitated this phase of analysis.

### **3.3.6 Assuring Rigor**

The PI (JA) and two co-authors (DB and RA) experienced in qualitative analysis independently coded portions of the transcriptions. The three coders then met to discuss and compare the coding decisions, and any disagreements were resolved through discussion followed by updating the codebook. The PI also consulted an expert in the emerging field of AL in health care (MT) to refine the codes.

To assure rigor further, findings were explored in meetings of the research team to make certain that the interpretations and hypotheses made from the analysis were sound. These methods were supported by behaviors described in **Table 3**, which we

used to maximize trustworthiness of the findings from this study.

**Table 3: Strategies for Assuring Rigor**

<b>Criteria</b>	<b>Strategies</b>
<b>Credibility</b> Findings are credible and accurate	<ol style="list-style-type: none"> <li>1. Prolonged engagement in the ICU</li> <li>2. Triangulation of data sources to increase depth and richness of data</li> <li>3. Independent coding by faculty mentor</li> <li>4. Peer debriefing by faculty mentor</li> <li>5. Explicit search for disconfirming evidence</li> </ol>
<b>Transferability</b> Findings applicable to other contexts	<ol style="list-style-type: none"> <li>1. Rich description of participants and context</li> <li>2. Reflect on usefulness, relevance and ethics of presentation of findings</li> </ol>
<b>Dependability</b> Findings are reproducible	<ol style="list-style-type: none"> <li>1. Audit trail</li> <li>2. Independent coding of portions of data by faculty mentor</li> <li>3. Weekly meetings with faculty mentor to explore divergent findings</li> </ol>
<b>Confirmability</b> Minimal bias	<ol style="list-style-type: none"> <li>1. Weekly meetings with sponsors to ensure data analysis reflects data collected</li> <li>2. Exploration of biases</li> <li>3. Audit trail: reflexive journal</li> </ol>

Note. Adapted from: Bloomberg & Volpe, 2008; Creswell & Plano Clark, 2011; Lincoln & Guba, 1985; Miles & Huberman, 1994

### **3.4 Findings**

The case patient was a 68 year-old Caucasian male with sepsis and multiple comorbidities, identified by the attending physician as unlikely to survive the ICU stay.

He subsequently developed aspiration pneumonia and adult respiratory distress syndrome (ARDS), and life support was withdrawn. The family members participating in the case were his wife, two sons, and one daughter-in-law. The HCPs participating in the family meetings included the bedside nurse (RN), a fellow, and a palliative care physician (PC). Family meetings occurred daily for three days. The first meeting, conducted by the fellow, occurred after the patient had an aspiration event and subsequent MI requiring him to be placed on ventilator support. The following day, when the patient had been diagnosed with ARDS, the PC and the fellow conducted the second family meeting. At the end of this meeting, the family members had come to understand that the patient was unlikely to survive. The third family meeting was conducted by the fellow and focused mainly on providing comfort care.

The AL behaviors identified in the analysis include: provide information, provide decision support, support realistic hope, and address work avoidance. Each of these behaviors is presented along with definitions and exemplars.

### **3.4.1 Provide Information**

The HCPs described the challenge to the family and presented information that was clear, honest, and in lay terms. In the first family meeting, the fellow described the adaptive challenge to the family:

A lot of what we do...here in the ICU, is we ...support the body until it can start working and heal...But when your body isn't able to do that, my ability to keep



your blood pressure up with medications and keep your lungs going with a ventilator doesn't help.

Providing prognostic information in clear language, free of medical jargon, allowed the family to understand that the patient may not survive and to prepare for making decisions about treatment.

In the family interview, the daughter-in-law expressed her appreciation for the honesty saying, "It's the way they deliver the information...they didn't sugar coat anything. They just told us everything we needed to know...It makes a big difference." The wife confirmed the importance of honest explanations, saying, "They can explain why it's terminal. They can give us the answers."

Giving the family members clear and direct information about the challenge, in lay terms, allowed them the opportunity to understand that they were facing the new reality that their loved one was dying and to begin to prepare for coping with this inevitable reality.

### **3.4.2 Decision Support**

The HCPs offered decision support in several ways. They explained the prognosis, identified and clarified risks and uncertainty, explained the available options and trade-offs inherent in those options, and helped the family to identify goals and values. These behaviors prepared the family members to make decisions based on the

reality of the situation.

During the first family meeting the fellow provided decision support when she discussed the prognosis for long-term survival and quality of life (QOL), explaining that, although the patient may survive this particular episode, he was unlikely to ever return home. Early in the second meeting the PC explained the prognosis for survival and QOL:

Both of his lungs have infiltrates, and that is a big concern. The other big concern is, he's not able to hold fluid in his system...his protein stores, something that we call albumin, is...a predictor...of how well people do. You need an albumin of at least 2; his is 1, so...we're looking at a life threatening situation, both in the short haul and then in the long haul what could be expected even if he survived this particular episode.

In this exchange, he described the challenge and then explained what it meant for the patient's prognosis, both short and long term. He also hinted that, although the patient may survive, he would likely have a poor QOL. By explaining the prognosis in this way, these HCPs allowed the family to begin to change their beliefs about the patient's ability to thrive and prepared them to make decisions that would affect the patient's outcomes.

In addition to explaining the condition and prognosis, the HCPs helped the family to identify options and make trade-offs that were in line with their goals and values. They accomplished this by exploring the goals and values of the patient and

family as well as identifying options for the family, including the continued use or discontinuation of life supportive measures, such as vasopressors, ventilator support, tube feedings, antibiotics, and diagnostic testing, as well as comfort measures. In addition, they discussed the trade-offs inherent in these options. These conversations included explanations of whether these technologies were effective in achieving their goals.

Toward the end of the first family meeting, when a family member asked how long the patient could remain on vasopressors, the fellow explored the goals of treatment and the desired outcome by responding:

I can keep him on blood pressure medication for a long time. The question is if that's what he wants or not... but the question becomes if he's getting a lot sicker..., we're going to keep going, but what are we going to keep going to? What's going to be our goal?

Along with exploring the goals, the HCPs described the available options and trade-offs inherent in those options. The fellow explained that focusing on keeping the patient's blood pressure up and trying to wean him from the ventilator could compete with providing adequate pain control. Another trade-off involved the family's desire to have a meaningful conversation with the patient. Son 2 asked if they could decrease the sedation so that they could have a conversation with the patient. In the ensuing conversation, the PC addressed the trade-offs as well as values and preferences:

This gets down to the values of the patient. So would he want to be able to speak

or would he want his shortness of breath controlled. 'Cause all the medicines that we give for ...shortness of breath, they are sedating and that's an issue.

This explanation allowed the family to recognize that, although they wanted very much to have a conversation with their loved one, doing so would involve a significant trade-off in the ability of the HCPs to keep the patient comfortable. This recognition allowed them to do the adaptive work of weighing the options and trade-offs and making the decision that they believed was best.

At the end of the first family meeting, the nurse fielded questions from the family. When asked if he was at risk of having another heart attack, she responded, "He is at risk for having another heart attack. I don't know how big or how small that would be...there's always the risk for another event." She described the challenge and then clarified that there were risks and uncertainties. This allowed the family to prepare for the possibility that the outcome would not be favorable. In addition, admitting that there was uncertainty, rather than giving false reassurance, allowed the family to trust her.

Identifying the options and trade-offs and introducing the risks and uncertainties fostered AW because it prepared the family to weigh the options and trade-offs as they made decisions that would have significant consequences for the patient. Clarifying the goals allowed the family to make a decision that was based on their goals and the expressed goals of the patient.

During the family interview after the final family meeting, the daughter described how the behaviors of the HCPs provided decision support when she said:

If they just told us what kind of decisions we had to make and then couldn't tell us what it would look like after we made those decisions, then I think it would be a lot scarier...But the honesty comes in again, and they just painted a picture of what could happen, and...it helps with the scariness of it."

Explanation of the prognosis, available options, and trade-offs, and exploration of the patient goals allowed the family to weigh the benefits and burdens of treatment options and make the decision that they felt was best.

### **3.4.3 Support Realistic Hope**

The HCPs supported hope by assuring that the patient and family would continue to be cared for, foreshadowing possible negative outcomes, helping the family to reframe hope from hope of survival to hope for a peaceful death, demonstrating compassion and empathy, allowing time to process information, and assuring adequate pain and symptom management.

During the first meeting, the fellow reassured the family that the patient was receiving and would continue to receive appropriate technical care to treat and attempt to reverse his illness, saying "Right now he's already on pretty broad-spectrum antibiotics,...and they will treat anything that's gone down into his lungs..." At the same time, she hinted that the outcome might not be favorable, saying "[This episode of

aspiration] puts a stress on a body that was already sick...I'm hoping that he'll get better, but it could go the other way as well, and then we would be having a very different talk." By use of foreshadowing, she gently and compassionately prepared the family for the possibility that the patient would not survive.

When the family asked about decreasing sedation to be able to have a meaningful conversation with the patient, the PC reframed hope for outcomes by saying, "I think the easiest and the shortest goal that is possible is that he could hear you. The more difficult would be to be able to hear and respond verbally." In this exchange, The PC reframed hope from hope for a meaningful conversation to hope that the patient could hear them and not struggle to breathe. The fellow responded to the same question by supporting hope for non-abandonment and adequate pain control when she said:

We can certainly decrease the sedation, and if he starts looking uncomfortable it goes back on very, very quickly. So I don't want you to think that if we do that he's going to be suffering for a long time while we're trying to get him comfortable again.

Assurance that the patient would be kept comfortable allowed the family to have hope that the patient would be treated with compassion.

The HCPs demonstrated compassion for the family members as well as the patient. When Son 2 said, "So it sounds like, (begins to cry) I'll be all right, it sounds like

there's no way he's ever going to get out of ICU no matter what?" The fellow responded, "The truth is, no. I wish that I could ...tell you something different. I wish that I could come here with an encouraging nod or say, 'he's gotten some better.'" This "wish" statement demonstrated compassion and caring for the family, allowing them to have hope that they would be treated well and cared for.

Another way of supporting hope and demonstrating compassion and respect for the family was to assure them that they had time to consider the decisions they faced. The HCPs reassured the family members several times that there was no rush and that the HCPs would be available to answer their questions and support them in their decisions.

The family described how the HCPs supported hope. The wife said, "And I think one thing that really helped is the compassion that she has. I know that she knew the pain that we [felt]..." Son 2 expressed not feeling abandoned when he said, "And you're not treated just as a client. You're treated more as a friend of the family."

By supporting hope through assurance of non-abandonment, foreshadowing, compassion, reframing hope, allowing time to process information, and assurance of adequate pain and symptom management, the HCPs were able to facilitate the family's adaptation to a new and frightening reality without removing hope.

### **3.4.4 Address Work Avoidance**

Several times during the three family meetings, one or more of the family members avoided AW by changing the topic and refocusing the discussion from AW to technical aspects of treatment. When this occurred, the HCPs responded by use of the behaviors identified above to support decision making, support hope, and strengthen the therapeutic relationship. Using empathy and compassion, they explained to the family what to expect and reassured the family that the patient would not be abandoned and that pain and symptoms would be managed. As the daughter pointed out in the interview, these techniques helped “with the scariness of it” so that the family was able to focus on the adaptive challenge. After using the supportive techniques, the HCPs then refocused the conversation on the AW that needed to be done and on the goals of the patient.

An example of this occurred during the second family meeting when Son 1 diverted the conversation from goals of care to technical aspects of the ventilator treatment. The PC answered the question, gave a brief explanation of the disease process and quickly shifted the conversation back to goals, saying:

The reason we’re even having any of this discussion is we don’t want him to suffer, and I can look at your faces and know that there’s a ton of compassion and love for this gentleman...our job is to find out what his wishes are and try to abide by that. So we have a job to keep you all informed and educated, [and] we have a job to make sure he’s not suffering because of what we’re doing to him.



In this response, he used empathy, compassion, and positive regard as ways to strengthen the therapeutic relationship and promote adaptation. Then he refocused the discussion to the AW that needed to be done.

### **3.5 Discussion**

When HCPs recognize an impending death and support the family's ability to do AW through AL behaviors, the family should be able to more readily face the adaptive challenge and do the AW required to navigate the transition from curative to palliative care. However, when HCPs instead focus conversations on technical solutions, the family members may not recognize that they are facing adaptive challenges and may have more difficulty doing the adaptive work necessary to make decisions on behalf of their loved one. The consequences for the patient may be prolongation of the dying process and increased suffering, for the family increased anxiety and stress, and for society increased cost of dying (Meier & Brawley, 2011; Nelson, Cox, Hope, & Carson, 2010).

Use of Adaptive Leadership is consistent with current standards for EOL care in the ICU, which are based on the premise that family/patient-centered care and shared decision-making are ideals (Davidson et al., 2007; Truog et al., 2008). In this study, we examined a case of withdrawal of life support in the ICU through the lens of AL and identified adaptive challenges and AL behaviors that facilitated family/patient centered

care and shared decision-making. By providing information in clear language, the HCPs ensured that the family members and the health care team had a shared understanding of the patient's prognosis and expected outcomes. By providing decision support, supporting realistic hope, and addressing work avoidance, the HCPs facilitated care that was centered on the goals of the patient and family.

We identified several difficult adaptive challenges faced by family members as the patient's condition deteriorated. These challenges included understanding that their loved one was not responding to technical interventions, changing their beliefs about their loved one's ability to thrive, identifying their goals and values for the patient, making trade-offs, reframing their hope from hope of survival to hope of peaceful death, and coping with loss and grief. Use of AL behaviors supported the family's AW as they navigated the transition from curative to palliative care.

Characteristics of the AL approaches used by the HCPs included use of clear, honest, and direct language to provide information about the challenge of patient's condition and explain that the technical solutions were failing to improve his chances of survival. This study provides evidence that this enabled the family to engage in AW beginning with understanding that they were facing an adaptive challenge.

In addition to providing information about the challenges, the HCPs used AL behaviors to facilitate AW by providing decision support. These behaviors included

explaining the prognosis and expected outcomes, describing the options available and the trade-offs inherent in those options, and helping the family identify and clarify their goals and preferences as well as expressed goals of the patient. These behaviors facilitated AW by providing a holistic understanding of the nature and consequences of the decisions. In response to these behaviors, the family accomplished adaptive work by gathering information, reevaluating what they hoped for, applying their understanding of the values of the patient to make a decision, identifying the patient's goals and making decisions based on those goals, coming to terms with the impending death, accepting that the patient was dying, and preparing to say good bye.

The HCPs in this study facilitated AW by supporting realistic hope. Although many people view hope in terms of an expected outcome, such as survival, hope may also be defined as trust or reliance on others, such as family, community, or a higher power (Tulsky, 2002). The HCPs in this study supported hope for an outcome by gently and gradually helping the family to reframe their hope from hope for cure to hope for peaceful death. They also nurtured a hope for trust and reliance on others by demonstrating compassion, empathy, and an abiding presence; assuring non-abandonment; foreshadowing; allowing time to process information; and assuring adequate pain and symptom management. By fostering realistic hope, the HCPs created the opportunity for the family to do AW without becoming overwhelmed with

hopelessness and despair.

Adaptive work is often avoided because it requires effort and might create fear and loss (Heifetz et al., 2009; Thygeson, 2013). Because of the adaptive challenges involving fear and loss faced by family of members of patients dying in the ICU, family members in this situation tend to avoid doing AW (D. E. Bailey, Jr., et al., 2012). This study illustrated some of the avoidance behaviors described in the AL framework, including changing the topic from AW to technical work. The HCPs responded to the family's avoidance in ways that supported the family while refocusing the discussion to the AW that needed to be done.

Because the AL framework is new to the field of healthcare, adaptive leadership behaviors have not yet been fully operationalized (D. E. Bailey, Jr., et al., 2012). The findings from this study offer preliminary definitions for the concepts in the AL framework in health care. By examining the interactions between HCPs and the family members through the lens of AL, using a taxonomy of AL behaviors developed by experts in the emerging field of AL in healthcare (MT), we were able to identify and describe adaptive challenges, technical challenges, adaptive and technical work, and specific AL behaviors used by the HCPs to facilitate this family's transition from curative to palliative care. Future studies building on this knowledge will help to develop the framework by further delineating these challenges and behaviors with the

ultimate goal of improving practice by providing useful guidelines to communicate with patients and family members who are facing adaptive challenges.

### **3.6 Conclusion**

When family members of a dying patient in the ICU have not recognized the need to do AW, they may continue to focus on technical solutions and insist on aggressive treatments. However, when HCPs recognize an impending death and support the family's ability to do AW through AL behaviors, the family is able to more readily face the adaptive challenge and do the AW required to navigate the transition from curative to palliative care. Use of AL techniques by HCPs throughout the trajectory of an ICU stay will help family members develop a realistic understanding of the prognosis, expected outcomes, the options, and the inherent trade-offs and to make decisions that are consistent with the goals of the patient and family.

This study is one of the first to use the AL framework to examine HCP behaviors and the first to use AL to examine the behaviors used by HCPs interacting with family members of a patient at EOL in the ICU. The findings are significant to the fields of critical care medicine, nursing, and palliative care because they provide a framework for understanding how to support family members and facilitate the difficult transition from curative to palliative care.

## **4. Family Perspectives of Nursing Strategies with Family Members of Patients Transitioning from Curative to Palliative Care in the Intensive Care Unit**

### ***4.1 Introduction***

In the United States 50% of people who die in hospitals, die during or after a stay in an intensive care unit (ICU) (Wunsch et al., 2009), and two thirds of ICU deaths involve a decision to limit treatment, either by withholding or withdrawing life-supportive therapy (Balboni et al., 2013; Balboni et al., 2007; Desteno et al., 2013; Prendergast et al., 1998; Prendergast & Luce, 1997). Because most ICU patients are not able to make decisions for themselves (S. Cohen et al., 2005; Delgado et al., 2009; Goold et al., 2000; Hiltunen et al., 1999), family members are left to make these difficult decisions. Because of the tremendous burden of making EOL decisions, family members might suffer from fear that their loved has suffered, fear that they have given up too soon, and lingering feelings of doubt, regret, and guilt (Braun et al., 2008; Kirchhoff et al., 2002). These vulnerable family members rely on healthcare professionals to guide them through the decision-making process.

The decision to initiate life support, often made in an emergency situation, launches the patient onto a trajectory of aggressive care that will persist until either the patient recovers or a decision is made to withhold or withdraw life support (Gutierrez, 2010). The term “trajectory” is used in health sciences as a way of understanding life

pathways characterized by varying levels of functioning (Clipp et al., 1992). Within these trajectories, people experience life events, such as a stroke or heart attack, that affect the overall trajectory (Clipp et al., 1992). Although a stay in the ICU might be seen as a life event, it also has its own trajectory. When a patient has a poor prognosis for survival, a decision to withhold or withdraw life support characterizes a trajectory of transition from curative to palliative care. These trajectories are marked by the time the patient spends in the ICU and by ICU events, such as a heart attack, blood clot in the lungs, organ failure, or cardiac arrest and are also influenced by the level of certainty that the physicians have that the patient is not likely to survive (Gutierrez, 2010).

In an ethnographic study of EOL decision-making in the ICU, Gutierrez identified four main trajectories of transition from curative to palliative care in the ICU (Gutierrez, 2010). The first trajectory is a trajectory of early certainty about the poor prognosis, with the physician(s) making a determination that the patient will not survive within the first 24 hours. This trajectory is rare because most physicians prefer to give the patient a chance to respond to treatment. The second is the trajectory of certainty within the first 72 hours. Physicians prefer to observe the patient's response to treatment over a period of 48-72 hours to identify trends before determining that the patient is not going to respond to treatment. The third trajectory is marked by a two week time period when typically a decision must be made whether or not to perform a tracheostomy. The

fourth trajectory is a lingering trajectory, where the uncertainty about prognosis persists past two weeks, often in situations with an unclear diagnosis or etiology. The more certain the physicians are about the prognosis, the earlier they initiate discussions about prognosis with family members (Gutierrez, 2010).

Nurses in the ICU are positioned uniquely to provide decision-making support to family members because they have the most contact with the patient and family. Nurses deliver care that is personal and intimate allowing them to develop trusting relationships with patients and families, to assess their needs (Puntillo & McAdam, 2006; Thelen, 2005), and to observe the responses that family members have to the changing condition of the patient. Nurses thus gain a unique perspective that places them in a position to support family members making EOL decisions, yet the literature provides little evidence of what strategies are effective in this population (Adams et al., 2011). Without knowledge of the strategies family members find helpful or harmful, nurses must rely on intuition to guide them in these conversations (Docherty et al., 2007) or avoid such discussions altogether. Failure of nurses to support family members effectively through this process might contribute to prolongation of the dying process, increased pain and suffering for patients, and increased emotional distress for family members

Although the nursing literature suggests that involving nurses in EOL decision-



making might be beneficial to family members, most of this literature has been conducted from the perspective of nurses rather than from family members, and few studies have involved direct observation of interactions between nurses and family members (Adams et al., 2011). Nurses believe that what they do is beneficial, yet nurses also use strategies that might be harmful, such as giving misleading facts without interpretation (Verhaeghe et al., 2007), giving personal opinions (Adams, Bailey, Gentry, et al., 2010), and telling family members that their loved one is being tortured (Robichaux & Clark, 2006).

Evidence from the medical literature on communication at EOL indicates that having difficult conversations with family members is a skill that must be learned, not something that is guided by instinct (Back et al., 2009). Some of these skills might translate to nursing practice; however, because the role that nurses play in this process is different from that of physicians, it is important to identify the specific strategies that are unique to the nurse and how family members respond to these strategies.

Understanding how family members respond to nursing strategies will contribute new knowledge for practice and intervention development. Thus, empirical evidence of what strategies are effective in supporting family members is needed so that nurses can guide their practice by knowledge of what works rather than practicing on instinct alone.

#### **4.1.4 Purpose**

The **purpose** of this study was to explore how family members making EOL decisions for their loved ones in the ICU responded to the nurses' communication and support strategies.

#### **4.1.5 Research Questions**

From the perspective of family members:

1. What specific strategies do nurses use when supporting family members making EOL decisions in the ICU over the trajectory of the decision-making?
2. How do family members describe these strategies as helpful or not helpful in supporting their ability to make decisions on behalf of the patient?
3. How do family members describe these strategies changing over the trajectory of decision-making?

### **4.2 Methods**

#### **4.2.1 Design**

I addressed the aims of this study using a prospective, longitudinal, qualitative descriptive design with narrative-style interviews and direct observation. I identified patients who were likely to need complex decision-making involving discussion of withdrawal or withholding of life support and interviewed the family members at intervals over the trajectory of the ICU stay beginning when they were identified as

being at high risk of dying and ending when one of the following occurred: (a) Life support was withdrawn, (b) The patient was discharged from the ICU, (c) A decision was made to undergo tracheotomy for respiratory failure (Nelson et al., 2007) or (d) the patient had been enrolled for two weeks. This design was intended to capture the time period when family members were most likely to be in the process of making decisions.

### **4.2.2 Setting and Sample**

#### **4.2.2.1 Setting**

Participants were recruited from two 16 bed adult medical ICUs, a medical ICU (MICU) and a surgical ICU (SICU) in Duke University Hospital in Durham, North Carolina, a tertiary care university hospital system. The visiting hours for families were liberal but limited to certain times of day. The nursing experience ranged from newly graduated to 20-30 years. The MICU is a “closed unit” meaning that the attending physicians who rotate through the unit manage all of the patients on the unit, whereas the SICU was not closed

#### **4.2.2.2 Sample inclusion exclusion criteria**

The target population was family members of patients in the ICU aged 21 or older who were likely to need complex decision-making involving discussions of withdrawal or withholding of life support. This eligibility was determined using an existing screening tool designed by ICU and palliative care nursing and physician

leaders with the intent of identifying patients who would benefit from a palliative care intervention that was based on literature review, survey of ICU deaths, and expert opinion (Norton et al., 2007). These criteria included the presence of one or more of the following: (a) ICU admission following a current hospital stay of >10 days, (b) age >80 with two or more life threatening co-morbidities, (c) diagnosis of an active stage IV malignancy, (d) status post cardiac arrest, or (e) diagnosis of an intra-cerebral hemorrhage requiring mechanical ventilation (Norton et al., 2007). In addition, because researchers have demonstrated that physicians are better able to discriminate between survivors and non-survivors than scoring systems (Sinuff et al., 2006), and because physicians often make a judgment that a patient is unlikely to recover or is probably going to die before having a discussion with the family about palliative care (Gutierrez, 2010), a sixth criterion “any patient who is deemed by the attending physician to be at high risk of dying” was added.

For this study, family member was defined as “those persons who are emotionally intimate or familiar with the patient” (S. Bailey, 2002, p. 484) and who were visiting at least five days per week. The healthcare team (nurses, physicians, and or social workers) were queried about the primary family member who was actively engaged in visitation and likely to be the primary person involved in the decision-making process, including family meetings. Because decisions often included multiple

family members (Abbott et al., 2001), any family member whom the primary family member identified as visiting regularly and likely to be involved in decision-making was invited to participate. Although some researchers in EOL care in the ICU use the criteria of legally authorized representative (LAR) or next of kin (Anderson et al., 2008; Azoulay et al., 2001; Limerick, 2007), others have used a more informal definition, such as people who consider themselves to be family (Fox-Wasylyshyn et al., 2005), who self-identify as significant others (Fry & Warren, 2007), or who were identified by the nurse as the family member involved in the decision-making (Counsell & Guin, 2002). The rationale for not using the LAR is that I wanted to capture those family members who were in the ICU on a regular basis, interacting with the nursing staff, rather than the legal decision-makers, who might or might not have been the ones interacting with the staff and making the decisions. Based on my pilot study (Adams, Bailey, Gentry, et al., 2010), this was an effective strategy to identify the family decision makers. Family members were excluded if they were unable to speak, read, and write English. In addition, family members under the age of 21 were excluded as they would not be able to consent for their family member, nor were they likely to be the person making the decisions.

#### **4.2.2.3 Sampling plan**

I used a purposive sampling technique with maximum variation (Patton, 2002;

Sandelowski, 2000) using attributes that might have affected how the family would respond to the nurse. Family member attributes of ethnicity, gender, socioeconomic status (SES), education, and religiosity have been shown to explain variation in attitudes towards use of life support (Schmid, Allen, Haley, & DeCoster, 2010; Steinhauser et al., 2000); talking about the meaning of death; controlling the time and place of death; discussing fears (Steinhauser et al., 2001; Steinhauser et al., 2000); presence of, understanding of, and attitudes towards advance directives (Kwak & Haley, 2005; Schmid et al., 2010); and the strategies used by family members in making decisions (Braun et al., 2008). Because I did not have direct control over the attributes of the family members, I varied the sample based on patient ethnicity and SES to obtain variation in family members. The ethnicity was stratified into 2 main groups, African American and Caucasian; socioeconomic status was based on presence or absence of private insurance (including Medicare with a private supplement). I attempted to recruit at least 2 cases of every combination of these 3 attributes (Sandelowski, 2000). Based on this strategy, the anticipated total number of cases was 20. (Charalambous, Papadopoulos, & Beadsmoore, 2008; Gutierrez, 2010; Limerick, 2007; Meeker, 2004). Because researchers have demonstrated that the occurrence of decisions to withhold or withdraw life support are 30-50% lower in persons under the age of 50 than in those over the age of 50, I attempted to recruit four patients under the age of 50. Data collection ended when I

had achieved an acceptable variation in participants and a redundancy of themes. I recruited a total of 17 cases. All 17 completed at least one interview, and five completed at least three interviews.

### **4.2.3 Data Collection**

#### **4.2.3.1 Ethical conduct**

I obtained IRB approval to conduct the study. After potential patients were identified through screening, the physician or nurse caring for the patient introduced the study to the family members. Although the family member(s) who participated was not necessarily the LAR, the LAR was contacted to give consent for the patient to be enrolled in the study so that I could review the patient's medical records. If the family agreed to participate, the PI explained the study to the LAR and to any family members who cared to participate and obtained informed consent.

#### **4.2.3.2 Family member interviews**

Narrative-style interviews (Bauer, 1996; Elliot, 2005; Flick, 1998; Jovchelovich & Bauer, 2000) were conducted with the family members at study entry and up to two additional episodes during the ICU stay. These interviews allowed the participants to control the pace and agenda for describing their experience. The participants were allowed to tell the story without interruptions using cues to encourage the participant to continue talking (Bauer, 1996; Jovchelovich & Bauer, 2000). After the narrative came to a

natural end, the interviewer asked some directed questions using the participant's words to clarify areas of interest (Bauer, 1996; Elliot, 2005; Flick, 1998; Jovchelovich & Bauer, 2000). The initial interview began with the grand tour question, "Tell me the story of how your family member came to be here in the ICU," followed by "tell me what it was like when you first visited your loved one in the ICU." Subsequent interviews focused on the individual's experience since the previous interview, such as, "what has happened since we spoke last?" or "what was it like when your nurse talked to you in the family meeting? How did that affect you?" I explored any statements about the nurse by asking questions, such as "what was it like for the nurse to say that. How did that help you?" See **Appendix A** for interview guide.

In addition to the questions on the interview guide, I also asked each participant to rate his/her hope on a scale of one to five, with one representing "no hope" and five representing "extremely hopeful." When/if the family member asked "hope for what," I asked them to tell me what they were hoping for, and we explored their hope. I also asked what, if anything, the nurses said or did that supported their hope. See **Appendix B, Hope Line**.

All interviews were recorded digitally. Unless the family members specifically requested to be interviewed as a group, each was interviewed alone to provide each with the opportunity to express problems, issues, or concerns that they might have been



uncomfortable expressing in the family group. In four of the cases, the family members requested that family members be interviewed together.

I interviewed the participants in a private area. Interviews were conducted at study entry, after a triggering event or periodically while the patient was enrolled, for a maximum of three interviews per family member.

#### **4.2.3.3 Demographic data**

I collected demographic data on all participants to describe the sample. For the patients, this included age, ethnicity, gender, SES, and diagnosis. To describe the family member sample, demographic data included education, ethnicity/race, gender, religion, previous experience with a close family member in the ICU, relationship to the patient, distance from the hospital, and regularity of visitation. These variables can be found in **Appendix C**.

#### **4.2.3.4 Patient monitoring and medical chart review**

During the time that each patient was enrolled in the study, I had daily contact with the providers (six days per week) to monitor the patient's illness and treatment status. During these informal interviews, I asked the bedside nurse and the physician responsible for care that day (either the attending physician or the fellow) to rate their hope for the patient's survival. Additionally, I conducted daily chart reviews to document the illness and treatment course. See **Appendix D**. The daily contact with the

provider and the chart reviews facilitated identification of triggering events and also identified prompts for interviewing.

#### **4.2.3.5 Observation**

I was present on each unit daily, for a minimum of six days per week, informally observing interactions among the healthcare team and the patient and family, engaging in informal conversations with the health care team and family members, and attending rounds as a way of gaining acceptance and better understanding the unit environment (Spradley, 1980). I recorded field notes during and after observing each family conference, attending rounds, observing the unit environment, and after each interview. The field notes consisted of descriptions of the physical space, the participants, ICU activity, objects, acts, events, time, goals, and feelings (Crabtree & Miller, 1999). See **Appendix E**. At the end of each day of observation and interviews, I reviewed the field notes and identified areas where follow-up was needed the next day.

### **4.3 Data Analysis**

The overall goal of the analysis was to explore how family members making EOL decisions for their loved ones in the ICU responded to the nurses' communication and support strategies. The data were analyzed using qualitative content analysis (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005).

### **4.3.1 Data Preparation**

The digitally recorded interviews were transcribed verbatim by a professional transcriptionist, and verified accuracy PI by comparing the transcription to the recorded interview (Sandelowski, 1995). The transcribed interviews, field notes, and other text data were stored in an electronic database. The team used ATLAS.ti qualitative data analysis software system (Silver & Lewins, 2009) to aid in coding, organizing, and managing the data. Each document was labeled by source (family member, patient) and by type (interview, observation).

### **4.3.2 Data Analysis**

#### **4.3.2.1 First level analysis**

Analysis began with a reading of each document as it became available from the transcriptionist. I read each document several times to gain an understanding of the whole context (Graneheim & Lundman, 2004; Sandelowski, 1995). During this initial read, I conducted manifest coding and also noted any latent concepts that became apparent (Sandelowski, 1995). To increase the trustworthiness of findings, throughout the entire coding process I used memos to keep an audit trail of any coding decisions and development of ideas about explanations and themes (Sandelowski, 1995). In addition, I used reflexive memos to explore assumptions (Hsieh & Shannon, 2005).

#### 4.3.2.1.1 Provisional coding

To answer the first research question, “What are the specific strategies that nurses use when supporting family members making EOL decisions in the ICU during trajectory of the decision-making process from the perspective of the family members?,” I used a deductive method called provisional coding (Saldana, 2009). Provisional codes are codes that have been determined prior to entering the field, and are based on literature reviews, conceptual frameworks, the researcher’s own previous experience, and results of pilot studies (Saldana, 2009). Although provisional codes are based on *a priori* concepts, they are not necessarily fully developed definitive concepts (Blumer, 1954). The term provisional indicates that during the coding process, changes might have been made to the definitions and understanding of these concepts (Saldana, 2009). Through my review of the literature (Adams et al., 2011) and my pilot study (Adams, Bailey, Galanos, Zomorodi, & Anderson, 2010), I was able identify three roles that nurses play: information broker, supporter, and advocate. Each of these concepts has corresponding attributes. From this data, I developed a preliminary codebook of these attributes with definitions, exclusions, and exemplars to guide my coding. **See Appendix F** for a sample of this codebook. Using these *a priori* codes as a provisional coding framework, I coded in a deductive manner identifying and tagging units of data

that demonstrated and described these nursing roles and strategies as perceived by the participants. During this phase, I remained open to new nursing strategies that might not have been in the literature or noted in my pilot study. In addition, I was open to redefining the codes. Thus, there are many *a posteriori* codes and operational definitions that emerged from this phase of coding.

#### 4.3.2.1.2 *Open coding*

Because the literature is unclear about how family members perceive and respond to nursing strategies, to fully answer research question one, “What are the specific strategies that nurses use when supporting family members making EOL decisions in the ICU during trajectory of the decision-making process from the perspective of the family members?,” and to answer research question two, “How are these strategies perceived by the family members as helpful or not helpful in supporting their ability to make decisions on behalf of the patient?,” I used a more inductive approach called open or initial coding (Bernard & Ryan, 2010). I began by examining the data in clusters to which meaningful concepts (codes) that were identified were attached (Graneheim & Lundman, 2004). The interview guide determined the boundaries of each cluster of data. Each question and its corresponding answer defined a cluster. When a participant changed the course of the answer, and it was obvious that the content was very different, I made this a new cluster. These codes took the form of

process codes, as I identified nursing actions and family members' responses to those actions (Saldana, 2009). The nursing strategies and roles that I identified in my previous work, as well as communication strategies identified in the medical literature, were used as sensitizing concepts to guide the search for empirical evidence of whether and how family members perceive these strategies (Blumer, 1954; Bowen, 2006).

#### **4.3.2.2 Second level analysis**

##### *4.3.2.2.1 Pattern coding.*

Once the data were coded using both *a priori* (structural) and *a posteriori* (open) codes, pattern codes were used to categorize the data and explore emerging themes (Saldana, 2009). The coded text were arranged into categories and subcategories based on how the codes were related (Hsieh & Shannon, 2005). Similar codes were placed together, examined, and given a new code to represent a category of these similar codes (Saldana, 2009). These categories and subcategories represent the manifest content of the data and were exhaustive and mutually exclusive (Graneheim & Lundman, 2004). In order to understand the latent content, or the underlying meaning of the data, categories were linked to emerging themes, which involved interpretation and explanation (Graneheim & Lundman, 2004; Kvale, 1996).

#### 4.3.2.2.2 *Longitudinal coding.*

The third research question, “How do these strategies change over this trajectory of decision-making from the perspective of the family members?” was answered using longitudinal coding (Saldana, 2009). This type of coding is used when a researcher wants to examine how a phenomenon changes over time and often involves constructing a matrix to compare data over time (Saldana, 2009). I examined the data over time by creating a trajectory line (Clipp et al., 1992) of the ICU stay.

I created trajectory lines for each case for which I conducted at least three interviews. Each of these trajectory lines represented the family members’ responses to the changes in the patient’s condition and the behaviors of the health care providers in a patient determined to be at high risk of dying in the ICU. Each line included the frequency of helpful strategies identified by the family member, the condition of the patient, significant events, and numerical measures of hope for survival from the family members, physicians, and nurses caring for the patient. These trajectory lines were examined to interpret how the family members’ perception of nursing strategies changed over the trajectory of the time the participants were enrolled in the study.

The combination of these inductive and deductive coding methods allowed me to expand on the existing knowledge to provide a greater depth of understanding of how family members perceive nursing strategies in the transition from curative to palliative care in the ICU.

#### ***4.4 Assuring Trustworthiness of Qualitative Descriptive Study***

The methods of assuring trustworthiness for this study included rigorous attention to the design of the study, with special attention to the congruency of the methodology with the purpose and research questions. In naturalistic inquiry, the researcher is the instrument and must demonstrate experience, training and flexibility (Lincoln & Guba, 1985; J. M. Morse, Barrett, Mayan, Olson, & Spiers, 2002; Patton, 2002; Shenton, 2004). The principal investigator (PI) had completed two doctoral level courses in qualitative methods and analysis. The PI had also received training in qualitative analysis from her two faculty mentors, experienced in qualitative analysis as well as training in participant observation techniques from an expert in qualitative interviewing and direct observation in nursing work settings. The PI demonstrated flexibility by use of an audit trail that tracked the entire process of data collection and analysis.

To further assure rigor, the PI used a modified version of the criteria developed by Lincoln and Guba (Lincoln & Guba, 1985) as a guide to maintain rigor throughout the research process (**See Table 4**). These criteria have been modified to be consistent with



the constructivist paradigm, where multiple realities are co-constructed (Angen, 2000; D. J. Cohen & Crabtree, 2008). For example, I did not use methods typically used to confirm or verify what I had interpreted because that would assume that there was one reality to be confirmed (Angen, 2000). Thus, triangulation was used to increase the depth of the data and provide a richer and more complete picture rather than as a way of verifying the data (Shenton, 2004; Tobin & Begley, 2004). Likewise, member checking was not used.

**Table 4: Strategies for Assuring Rigor**

<b>Criteria</b>	<b>Strategies</b>
<b>Credibility</b> Findings are credible and accurate	<ol style="list-style-type: none"><li>1. Prolonged engagement in the ICU</li><li>2. Triangulation of data sources to increase depth and richness of data</li><li>3. Independent coding by faculty mentor</li><li>4. Peer debriefing by faculty mentor</li><li>5. Explicit search for disconfirming evidence</li></ol>
<b>Transferability</b> Findings applicable to other contexts	<ol style="list-style-type: none"><li>1. Rich description of participants and context</li><li>2. Reflect on usefulness, relevance and ethics of presentation of findings</li></ol>
<b>Dependability</b> Findings are reproducible	<ol style="list-style-type: none"><li>1. Audit trail</li><li>2. Independent coding of portions of data by faculty mentor</li><li>3. Weekly meetings with faculty mentor to explore divergent findings</li></ol>
<b>Confirmability</b> Minimal bias	<ol style="list-style-type: none"><li>1. Weekly meetings with sponsors to ensure data analysis reflects data collected</li><li>2. Exploration of biases</li><li>3. Audit trail: reflexive journal</li></ol>

Note. Adapted from: Bloomberg & Volpe, 2008; Creswell & Plano Clark, 2011; Lincoln & Guba, 1985; Miles & Huberman, 1994

## **4.4 Results**

### **4.4.1 Sample**

The data for this study were collected between October 2012 and February 2013.

**Tables 5, 6, and 7** summarize the sample. The sample consisted of 17 cases. Each case included one patient considered at high risk of dying and at least one family member. I completed 42 interviews of 32 family members. Of the total 49 participants (32 family members and 17 patients), 37 were Caucasian, and 12 were African American. Twenty-nine participants were female, and 20 were male. The age of the patients ranged from 23 to 78.

Of the 17 cases, seven (40%) survived to be discharged from the hospital. Of these seven who survived to discharge from the hospital, two had a decision to limit life supportive care while in the ICU. The remaining five were discharged from the ICU without the family having made an EOL decision. Of these same seven patients who were discharged from the hospital alive, only two were expected to make a full recovery to baseline; the remaining five had one or more chronic illnesses, including cancer, chronic obstructive pulmonary disease, chronic kidney disease, and dementia; and one of those five died several days after discharge.

Of the ten patients who died in the hospital, eight died in the ICU. Of these eight ICU deaths, five involved a decision to withdraw or withhold life support or a decision not to escalate life supportive treatment. These decisions included a decision to remove the endotracheal tube in hopes that the patient would survive but not re-intubate if the patient did not do well (so called “one-way extubation”), a decision not to

aggressively treat infection, or a decision to withdraw life support. Only one of the patients who died in the ICU received cardiopulmonary resuscitation (CPR); the remainder had do not attempt resuscitate (DNR) orders prior to their death. Of these eight patients who died in the ICU, four died after a prolonged ICU stay of two weeks or more.

**Table 5: Description of Cases**

Patient ID	Description of Patient	Family Members	Decision to limit or withdraw	Disposition
P1	72 y/o CM Aspiration pneumonia	Wife	No	Discharged from ICU
P2	49 y/o A F Altered Mental Status of unknown etiology	Sister-in-law and brother	No	Died after prolonged ICU stay
P3	55 y/o CM COPD and ARDS	Wife, 2 sons, daughter	No	Died in ICU after 5 days; CPR
P4	58 y/o CF relapsed AML	Husband	W	Died in ICU after prolonged ICU stay
P5	65 y/o CM hepatic failure, MOSF	Wife, Sister	L/ DNR	Died in ICU
P6	76 y/o CM pneumonia, CKD	Friend/HCPOA, Friend, 2 sons	L/OWE	Discharged from ICU; died several days later in hospital

Patient ID	Description of Patient	Family Members	Decision to limit or withdraw	Disposition
P7	71 y/o AA F s/p cardiac arrest	Daughter	No	Discharged from ICU
P8	70 y/o CM s/p cardiac arrest	Daughter, Partner	W	Died in ICU
P9	50 y/o AAM with relapsed Acute Lymphocytic Leukemia	Sister	L/avoid intubation/ DNR	Discharged from ICU; Died in hospital
P10	23 y/o CM MVC	Mother	No	Discharged from ICU
P11	65 y/o CM with Hepatitis C hepatorenal Failure, MOSF	Wife	L/OWE	Died in ICU
P12	65 y/o AAM Stage IV lung cancer	Wife, Daughter	L/DNR	Died in ICU
P13	72 y/o CM Neurological disorder, aspiration pneumonia	Wife, 3 Daughters	L/OWE	Discharged from ICU
P14	70 y/o CF Ischemic Bowel	Son, Daughter- in-law, Granddaughter	W	Died in ICU
P15	59 y/o AAF Pulmonary Hypertension	Daughter	L/DNR	Died in ICU
P16	33 y/o CM with ARDS	Mother	No	Discharged from ICU

Patient ID	Description of Patient	Family Members	Decision to limit or withdraw	Disposition
P17	46 y/o CM with ALL	Wife	No	Discharged from ICU

Note. L=limit W=Withdraw OWE=One Way Extubation DNR=Do Not Resuscitate  
y/o = age A=African AA = African American C = Caucasian M= Male F = Female  
MOSF = Multiple Organ System Failure

**Table 6: Patient Demographics (n = 17)**

Gender		Race		Age			
Female	Male	African American	Caucasian	<51	51-60	61-70	71-80
5	12	5	12	5	3	4	5

**Table 7: Family Member Demographics (n = 32)**

Gender						
Female	Male					
24	8					
Race						
African American	Caucasian					
7	25					
Education						
<12	12-15	>16				
1	28	3				
Annual Income						
4-9 K	18-30 K	30-60 K	>60 K			
1	2	10	19			
Relationship to Patient						
Spouse	Domestic Partner	Adult Child	Sibling	Parent	Other	
8	1	13	3	2	5	
Age						
21-30	31-40	41-50	51-60	61-70	71-80	Unknown
4	3	10	6	5	3	1

In the first section of the findings, I present the family member's descriptions of nursing strategies and their responses, represented by five categories: Demonstrate Concern, Demonstrate Professionalism, Build Rapport, Provide Information, and

Support Decision-Making. Table 8 contains definitions of the responses to strategies. Tables 9-13 summarize the strategies and the responses to the strategies, on which I elaborate following the tables. In section 4.5, I present the trajectories of the family members' descriptions of nursing strategies and their responses over time.

**Table 8: Responses to Strategies**

<b>Response</b>	<b>Definition</b>
Cope	FM indicated that the behaviors made them "feel better" or "deal with" the situation. Includes an expressed ability to be able to rest and sleep or take care of themselves. Also includes ability to provide support to other family members.
Closure	FM indicated that the behaviors led to their being able to feel at peace with the death of their loved one without a sense of unfinished business
Make Decisions	FM indicated that the behaviors helped them to make EOL decisions
Accept	FM indicated that the behaviors helped them to accept that the patient was dying
Afraid to Ask Questions	FM indicated that behaviors led them to feel uncomfortable or afraid to ask questions. FM indicated that they felt like they were a bother
Comfortable Asking Questions	FM indicated that behaviors led to their ability to feel comfortable and to be encouraged to ask questions
Confidence in nurse	FM indicated that the behaviors contributed to their ability to trust that the nurse would provide skilled and personalized care to the patient.
Difficulty Coping	FM indicated that the behaviors caused them to experience stress, anxiety, anger, difficulty sleeping, or other strong emotions.
Dissatisfied	FM indicated that the behaviors led to their feeling dissatisfied with the care by that nurse
Feel Judged	FM indicated that the behaviors caused them to feel that the nurse had a negative view of the FM's decisions or actions.



<b>Response</b>	<b>Definition</b>
Hopeful	FM indicated that the behaviors led to their ability to have hope. Hope might include hope that patient would get better, hope that patient would get good care, hope that patient not suffer, or hope that the FM would be cared for with love and concern.
Informed	FM indicated that the behaviors helped them to understand the patient's condition.
Lack of Trust and Confidence	FM indicated that the behaviors caused them to have a fear that they and/or their loved one would not receive the care that they wanted or needed.
Personal Connection	FM indicates that behavior allowed them feel a sense that the nurse was more than just a person taking care of their loved one's physical needs. Described nurse as like a friend.
Prepared	FM indicated that the behaviors helped them to feel emotionally and cognitively prepared to hear the news that their loved one would not survive.
Satisfied	FM indicated that they were pleased with the care that the nurse provided.
Trust	FM indicated that the behaviors gave them a sense that the nurse would be there for them to provide information and support
Uninformed	FM indicated that behaviors led to their lack of understanding or misunderstanding the condition of the patient
Unprepared	FM indicated that the behaviors led to them feeling unprepared for hearing news that the patient was not going to survive. Might have felt dismay or confusion.
Delay Decision-Making	FM indicated that behaviors led to a delay in the decision to withdraw or withhold life support.

Note. FM = Family Member

#### **4.4.2 Approach: Demonstrate Concern**

The family members described behaviors that demonstrated concern or lack of

concern for the physical, emotional, psychosocial, and spiritual well-being of the family and the patient. (See Table 9) When family members perceived concern, they expressed an ability to cope, to have trusting relationships with the staff, and to feel confident that the patient was receiving not only skilled care but personalized care.

#### **4.4.2.1 Physical well-being**

Family members expressed appreciation for the nurses' attentiveness to the physical needs of the patient, including attention to hygiene, comfort, and safety. Witnessing the nurse providing oral hygiene, combing the hair, changing the position and perceiving that this care was delivered in a gentle manner reassured them that their loved one was receiving personalized and competent nursing care. One family member described the nurse asking her about the patient's baseline behavior so that the nurse would be able to know when the patient might be uncomfortable or agitated:

The nurse said, "please explain what I should be looking for, what is his normal way? What are you experiencing with him, when you're with him." And I [said], "well he scratches his head all the time and is forever scratching and licking his moustache. And that's when he's aggravated...and you'll see that behavior." But he/she was concerned about what to look for. And I was impressed with that, he/she wasn't just saying "well he's here, and I'm going to take care of him with what I see, I'm going to go a little bit further" ...definitely involved with what was going on, and I felt like he was more comfortable because if he/she's a step ahead of him that's good... He/she was going to follow through. (Friend of P6, Single Interview, Day 2)

The nurses' attentiveness to the physical needs of the patient increased their confidence

in the care that their loved one was receiving. Some family members expressed that this confidence helped them to cope, to trust, and to rest and sleep at night knowing that their loved one was in caring hands. In addition to the care of the patient, family members described that the nurses' attentiveness to the physical needs of the stressed family member helped to develop trust and to cope.

Although most of the family members were very pleased with the care, some were dissatisfied with particular nurses whom they described as being impatient or rough with the patient or avoiding patient care. Two family members in particular described nurses who did not show concern for the patient. One family member described a nurse being very impatient with her husband:

And then yesterday, as soon as he got here, he [patient] was squirming like this, [the nurse] said, '...we can't have him squirming like that.' Nobody else has had that reaction to him. They are like, 'okay he is a little agitated.' 'Well we just can't have that.' And that's when it's time to leave at night, and I'm like, 'do I really want to leave him?' And I have actually even thought of asking the charge nurse to change him to someone else because that doesn't leave you [with] a good feeling, it doesn't me. Not good. (Wife of P11, Second Interview, Day 8)

Another family member described a nurse avoiding suctioning her father, instead telling the daughter "you can do that if you want to." Both of these participants expressed dissatisfaction and a lack of trust and confidence in the nurse.

#### **4.4.2.2 Emotional well-being**

Family members described nurses supporting their emotional needs by

acknowledging the family members' emotions and demonstrating empathy. One family member described the relief he felt at being able to share his emotions with the nurse:

I guess mainly I have tried to like keep my stuff together for my sister and for my mom and my brother. So, having somebody else that I can kind of, I don't know, be the one that's all together. It's nice to kind of, let my guard down. Let them know that I'm scared, or nervous, or anxious, or whatever. I don't want to let everybody else know that. (Son1 of P3, Single Interview, Day 2)

Other descriptions of feeling supported emotionally included the nurses showing their own emotions, validating the family member's love and concern for the patient, and staying with the family member in a crisis. Providing emotional support in these ways helped these family members to cope and to trust the nurses.

Several family members described nurses providing emotional support to the patients by talking directly to the patient in a soothing voice, reassuring the patient, encouraging the patient, and telling the patient what the nurse was doing. Several nurses encouraged the family members to talk to the patient and reassured the family that, although the patient might not respond, he/she could likely hear what was being said. One exception was a nurse who told the wife of a dying patient that he could not hear her:

We always just come in and get right down in his ear and say, 'Hey how are you? We're here.' [The nurse] was around the corner, he/she came up and said, 'he can't hear you.' And I'm like, 'well I don't care if he can hear me or not, I'm still going to talk to him.' 'Well he can't hear you.' Oh, it pissed me off. I don't care whether he can hear me or not, if I'm, if I want to talk to him, I should..., don't come in here and tell me he can't hear me. I don't care whether or not he

can hear me, it makes me feel better, you know? (Wife of P11, Second Interview, Day 8)

This encounter contributed to a lack of confidence and trust in the nurse and left the family member feeling angry and agitated.

Several family members described nurses supporting their emotional well-being by providing reassurance that the patient was receiving excellent medical and nursing care, which helped them to cope with difficult situations. Family members also described nurses being optimistic in their outlook, focusing on what could be done rather than on what could not, and providing reassurance that the patient would survive or vague reassurances that “everything would be okay.” The optimistic outlook and reassurances helped the family members to cope and provided them with hope. In one situation where the nurse provided reassurance that the patient would survive the family member believed it led to false hope:

I’ve heard [the nurse say], ‘Darlene, keep your faith up,’ that he/she has a member of his/her family very sick, and they came back...If I had not heard that doctor that day, I would have thought, oh that’s wonderful but I think he/she was giving her false hope. (Sister of P5, Second Interview, Day 13)

#### **4.4.2.3 Psychosocial well-being**

Family members described behaviors that demonstrated support for the psychosocial well-being of the family members individually as well as support for the family unit. Nurses asked family members about their social situation at home and

asked if they needed support at home. Nurses demonstrated concern for the needs of the family as a unit by bending the rules, such as allowing family members to be with patients outside of the posted visiting times, allowing more than two family members in the room at one time, allowing family members to stay in the room during procedures, and encouraging family members to participate in the care of the patient. One wife described how important it was that her family be allowed to visit together:

I know that there is a rule that there is only two visitors in there, but for me and both kids to be able to be in the room at the same time and not have to separate us as a family, just bending those rules a little bit here and there means a lot so we can be there together... It helped me be with my kids...for their support because they are 20 and 23, and they are looking at losing their dad, and they are really struggling... We need to be together as a family right now, and that allows us to be there. (Wife of P11, First Interview, Day 4)

In a later interview, this same family member described one nurse who was rigid about the visiting hours; she said, "We want to be with him. I mean if our time is limited, we want to be with him every minute we can be with him." (Wife of P11, Third Interview, Day 12) Allowing the family to be together as a family unit was important for the members of the family to cope with this difficult situation and make decisions as a family unit.

Another way that family members described nurses showing concern for their psychosocial well-being included encouraging family members to engage in coping behaviors, such as taking care of themselves and allowing themselves to cry and express

their grief. Several family members also described nurses being willing to go beyond what they believed was required, doing extra things to assure that the patient and family members had what they needed. This included simple acts, such as going into the waiting room to tell a family member that they could come in and visit the patient. Family members responded to these nursing behaviors by expressing trust that the nurses cared about them and would be a supportive presence for them.

#### **4.4.2.4 Spiritual well-being**

Family members described behaviors that demonstrated respect and concern for spiritual needs and practices, such as encouraging the family member to pray or read their spiritual books. One family member described how important this acknowledgment of her faith was to her ability to have hope for her father and to have trust and confidence in the nursing care:

Even when Claude came in, we had gotten a prayer cloth that we wanted to put a blanket over him, [the nurse] explained that that was fine but that also his temperature had been going up that's why the room was so cool so it may be removed. But he/she honored her request to put it over him and understood that...From my experience I understand the medical side of things, but I also believe in the spiritual side that God Almighty has the last say so....It's more of 'I can relate.'...Even when the nurse came to tell what my father had done he/she also made the comment 'continue to pray,' so that lets me know that you too know the powers that God has as well and that prayer can change things... It makes you feel good because I think one of the biggest things that we've always heard is that faith, and the determination of the patient can also go a long way. (Daughter of P12, First Interview, Day 3)

The family members described various strategies that demonstrated concern for the physical, emotional, psychosocial, and spiritual well-being of the patients and family members. When family members perceived that nurses were demonstrating concern, they reported that they had confidence that the nurse would take care of their loved one and trust that the nurse cared about the family member. They also reported better ability to cope with the stress of having their loved one in the ICU. When family members experienced a nurse whom they perceived was not caring, they lacked trust and confidence in that nurse and had more difficulty coping. Optimism, a strategy that demonstrated concern for the family member's emotional well-being, was seen as positive by some but as negative by one family member who believed that it led to false hope.



**Table 9: Approach: Demonstrate Concern**

Strategy	Exemplar Quotes	Response
<b>Physical:</b> FM described behaviors that supported the physical well-being of the patient and family members		
<b>Assure Patient is Comfortable:</b> FM described the nurse assuring that the patient's comfort needs are met, such as attending to mouth care, turning, and providing pain medication.	They've all been careful with, with my dad, I've noticed that. Maybe it's just because I'm in there, but whenever I'm in there, there's not a lot of jerking him around, not a lot of moving him around, communicating with him as well. Whenever they do something they usually say it, whether he responds or not is a different story, but they always say it... But, yeah, they have treated him, that's my main concern is how they have been treating him very well. (Son2 of P3, Single Interview, Day 2)	Cope, Confident
<b>Assure Patient is Comfortable</b>	[Name of nurse ] exceptional nurse, I really love him/her because he/she really shows like genuine care for my mom. Any time he/she comes in he/she puts the little...makes sure her hair is washed and cleans her up real well and ...always asks is she comfortable, gets her to wiggle her toes and move her hands and things. My mom responds to him/her better than anybody else that I've seen really. (Daughter P15, Third Interview, Day 14)	Cope, Confident

Strategy	Exemplar Quotes	Response
<p><b>Concern for FM Needs:</b> FM described the nurse demonstrating concern for the FM's physical needs, such as thirst, hunger, fatigue.</p>	<p>They even, like yesterday I mentioned to the day shift nurse that you know 'heck I haven't eaten anything today; I haven't thought about it.' Well the night shift nurse asked me had I eaten anything? That's incredible to me. They care about me. And they're not just here drawing a paycheck. They care about, they care about the patient; they care about the family. They have for me, and I've just been extremely impressed and surprised. ... it makes me feel valued. And like I said, it reassures me. And I've needed that. I've got a lot of faith, and that's what's getting me through a lot of this, but still you need that human interaction, knowing that people care about you, you know? And knowing that I'm sitting out there, wondering what's going on, and if something is getting ready to happen or whatever, they come out there and get me you know? And stuff like that. They don't have to do that, so it makes me feel really good to be here and that my mom's here. I know that in a sense that they're taking care of me too because they care about my feelings and what's going on with me. (Son of P14, Single Interview, Day 5)</p>	Cope, Trust
<p><b>Concern for FM Needs</b></p>	<p>[The nurses were very just caring and concerned, and I mean they treated the family like they were treating a patient, they were just I mean wonderful...: Gosh in every way possible, to make sure you were comfortable, if there's anything they could do, and they provided blankets and pillows if you were staying at night and just always checking to see if everything was okay; they were just real considerate, very considerate. (Wife of P5, First Interview, Day 5)</p>	

Strategy	Exemplar Quotes	Response
<b>Suggest that Patient Needs to Rest:</b> FM described the nurse recommending that the FM go home and let the patient get some rest.	Although, [the nurse] just told me...“don’t overdo it just talk to them but then take a break.” ...so I was a little surprised that he/she would say that, but he/she’s right I’m sure...I think he/she was just doing his/her job, and clearly he/she must know um...that I mean I was probably talking to her for a good five or ten minutes, and the nurse was doing things, and I was talking to the nurse, so maybe it was a lot of stimulus for Margaret, uh in that ten minutes or so and, and he/she felt like maybe that was enough for her at this time...I was a little annoyed perhaps but not really. That, I just sort of like well how’s my talking going to tire her out kind of thing, not, maybe for a split second kind of thing, think about that but once I thought about it, it makes sense they could, even something like somebody hovering over you and talking to you constantly could be, if you’re in that situation could be, could be a lot after a few minutes. Certainly after five or ten minutes, maybe he/she was saying don’t stand there for twenty minutes talking to her it’s just not, it’s not uh... they can’t take it all in; it’s almost too much for them. (Husband of P4, Second Interview, Day 7)	Dissatisfied
<b>Suggest that Patient Needs to Rest</b>	And they didn’t hesitate because if I needed to leave out, they explained ‘we’re going to try to give him some medicine, let him rest or whatever, and so you’ll probably just have to go out for a little while because he knows you’re here, and he’s not going to, going to be trying to make sure you’re still over there or something.’ So I just explained that I’m gonna go so he can rest. Because they wanted to know-wanted me to know that they’re not trying to put me out but they’re thinking about him. (Wife of P12, First Interview, Day 3)	Confident in Care
<b>Suggest that Patient Needs to Rest</b>	Well he/she was letting us visit, and he/she kind of got to a point, that like, “well you know maybe I want Mr. Johnson to just rest.” ... And he can hear you, and that’s fine, but I think I just really want him to really completely rest and just focus on him.” And so we all took that as fine, we’re exhausted, we’re going home. And that’s what we did. And that was good, that worked out...To go home and permission to get some other family members out of here that really needed to get out of here and needed to have a break from it. (Wife of P3, Second Interview, Day 4)	Cope

Strategy	Exemplar Quotes	Response
<b>Neg_Avoid Patient care:</b> The FM described the nurse avoiding patient care	D1: We walked in, and my dad was extremely dry; I mean just...like a just like he'd been in this Mojave desert for ten years. And he was choking, where they were trying to suction him out, and the nurse was just kind of playing on his/her computer- 'Well you can do that if you want to'... And my dad was choking, and I said for me to have to say 'are you going to do something? Like move or I'm going to come and move you,' ...and I went straight to their house and said 'what did you think about that nurse,' and she said, 'I didn't have a good feeling, and I said, 'me either and here's what happened.' And then she started sharing what happened to her, and we had not compared those notes until later at shift change, and I said 'you know what, that's not right,' ... D2: Uhuh, and here he is, he's having extreme trouble breathing, the rattle, and I was jumping up and down trying to suck it out of the back of his throat. He was sweating profusely, and his temperature had gone up a little bit, and he/she said 'oh you can put a wet rag on him if you'd like.' What the [expletive] are you getting paid to do? ...And then we're sitting there doing this, my husband's with me, and he/she's turned his/her back talking to the nurse next door. And I am, my anxiety and temper went out the roof. And I looked at my husband and said 'what the hell is going on here.' Really, all of the other nurses have kept their eyes on him. And he/she's got his/her back, and I'm watching the clock twenty minutes later they're still chit-chatting about transfers, job openings, this that and the other. Like okay there's family here I can take a break. I was livid....Oh yeah I had to do all that too. I had to keep his mouth...And I knew when I left, they weren't going to get it done. (Daughter1 and Daughter2 of P13, Second Interview, Day 8)	Lack of Trust and Confidence, Dissatisfaction, Difficulty Coping
<b>Neg_Rough with Patient:</b> FM described the nurse as being rough with the patient when providing patient care	Uh to me on the rough side, um doesn't say anything does, does whatever needs to be done. Uh...just not the caring, does not appear to be at all caring; I just really don't think he/she has um...I've had one you can tell they just don't care, they come in and just do their thing, and they're not even gentle with the patient just rough, rough... Just goes in, whips out his arm, puts a pillow under it, puts it down and goes out there and I mean is pretty much you know. (Wife of P5, Third Interview, Day 11)	Dissatisfaction, Lack of Trust and Confidence

Strategy	Exemplar Quotes	Response
<b>Emotional:</b> FM described behaviors that supported the patient's and FM's emotional well-being		
<b>Acknowledge FM Feelings:</b> FM described the nurse acknowledging the FM's emotions and allowing the FM to express grief, fear, etc. without judgment.	He/She listened to me, he/she listened to what I had to say and..when I needed, or he/she seemed to understand when I was about to cry. When I needed that extra pat on the shoulder or...that extra look across the room, he/she seemed to be very in tune with that, and that was just that connection and. (Daughter2 and Daughter3 of P13, Third Interview, Day 11)	Cope, Trust
<b>Acknowledge FM Feelings</b>	I guess mainly I have tried to like keep my stuff together for my sister and for my mom and my brother. So, having somebody else that I can kind of, I don't know be the one that's all together. It's nice to kind of, let my guard down. Let them know that I'm scared, or nervous, or anxious, or whatever. I don't want to let everybody else know that. (Son2 of P3, Single Interview, Day 2)	Cope, Trust
<b>Empathy for Patient and FM:</b> The FM described the nurse demonstrating empathy and compassion either through words, tone of voice, or body language	And that wears you down, you're exhausted, and you can't think anymore. He/she lifted the weights off my shoulders for me. 'Let me take it from here,' that's what he/she said, 'let me take it from here, I will, I will take care of your baby. I know he is your, he will always be your baby.' I said, 'yes he will.' 'Let me take care of him, I have this, you go get rest,' that's what he/she said. 'You need the rest, and tomorrow you can come back in...I am here all weekend 7-7.' I was relieved. Do you know what I mean? I thought, okay somebody has him and understands exactly what I mean when you can't explain yourself other than cry and say, 'this is my baby.' It doesn't make sense to somebody. But I knew he/she knew what I needed to hear, and he/she, she did his/her job. (Mother of P10, Single Interview, Day 2)	Cope, Trust
<b>Empathy for Patient and FM</b>	When we told him/her that he/she was doing a good job, and he/she was like, "thank you, I try to think of myself in the patient's point of view and like what I could do to help them better," and so, that was, that was a reassuring answer and kind of like a personal thing. (Son1 of P3, Single Interview, Day 2)	Confident

Strategy	Exemplar Quotes	Response
<b>Optimistic:</b> The FM described the nurse as focusing on the positive and on what can be done.	Yeah, I've been here a little bit more, and each one, if you ask, 'well it's been a better day,' or even if the first four hours were crap, they would let you know but not dwell on it and give you the hope that 'okay since the last four hours have been much better,...'working towards a positive instead of a negative, and I have seen that out of many of the girls, the nurses. More positive feedback instead of negative feedback. (Daughter 2 of P13, Second Interview, Day 11)	
<b>Reassure:</b> FM described that the nurse reassured the FM that the patient would get better and/or would receive good care.	I think they've been really good about...they've given me a lot of examples of other people, not any names or anything like that, just more like, 'we've got some people that have come in almost exactly like your husband' and, 'yeah it's a battle to get through this, but it can be done. We've seen a lot of this this year.' So that kind of gives me comfort in that they have developed some fine techniques about how to deal with things. And they are on the lookout for certain things, so they will be able to respond to them quickly and stuff like that. (Wife of 17, First Interview, Day 3)	Confident, Hope
<b>Reassure</b>	They showed genuine concern, and the nurse was like, 'we have someone here that's going to, that gets, that watches your mom.' Like basically the same thing I was doing at the other hospital; he/she was saying that they have someone here that does that, just watch her and make sure nothing happens or make sure that she is not, her pressures and stuff still the same. (Daughter of 15, First Interview, Day 2)	Cope, Confident
<b>Reassure</b>	I've heard [the nurse], 'Darlene, keep your faith up,' that he/she has a member of his/her family very sick, and they came back...If I had not heard that doctor that day, I would have thought, oh that's wonderful but I think he/she was giving her false hope. (Sister of P5, Second Interview, Day 13)	False Hope
<b>Show Emotions:</b> FM described the nurse showing his/her own emotions to the FM	And he/she even got teary-eyed with me; I've never seen a nurse do that; they're supposed to be-you know they're not supposed to get emotional through these times and stuff; they're supposed to be firm, but I've seen him/her get teary eyed and stuff. I could just see the care. I could see that he/she cared. (Daughter of P15, Third Interview, Day 14)	Trust

Strategy	Exemplar Quotes	Response
<b>Stay with FM in a Crisis:</b> FM described the nurse staying with them in a crisis to provide support.	It was very, it was very frightening, it was very frightening, but everybody here, they were just wonderful...And then the nurse, Bob's nurses at that time on that shift, and the doctors also had a medical student or somebody following her, so it seemed to me that the nurses and the medical students sort of had charge of me. Just sort of my needs and was I doing ok, and standing with me, and explaining to me what was going on. (Wife of P3, First Interview, Day 2)	Cope
<b>Talk to Patient:</b> FM described the nurse talking to the patient when he/she is doing care	I like it when they talk to him, when they interact with him, even though he is not interacting a whole lot... And I think that brings the best out in him. I mean it's, it engages him, and that's really important. And most people are good, they come in and they say, 'I'm giving you your medication or I'm going to do this, and I'm testing your blood, or I'm going to prick you.' They have been good about that. (Domestic Partner of P8, Single Interview, Day 9)	Confident
<b>Neg_Blunt:</b> FM described the nurse giving information about poor prognosis without preparation or compassion	I called and [the nurse] said...well he has requiring 16 of PEEP and he's on 60% of FIO2 and he's only Satting 89%. And I'm like, "okay?" He/she's like, "and the next step is the oscillator." I'm like, I know that if it ever progressed to that, that there is not, that doesn't mean the end for him, but that's very serious, and then the fact that he has COPD is a little bit of a contraindication to the oscillator. So, in my mind I'm thinking, "Oh my God." But he/she's like, "he's not actively crumping." I'm like, "but what you just said to me, like as a family member who knows a little too much and is not thinking clearly, that is very scary." (Daughter of P3, Single Interview, Day 3)	Difficulty Coping
<b>Neg_Pessimistic:</b> FM described nurse focusing on negative aspects of patient's illness	Um...just talking about the type, the diagnosis and well the white count is up, and they're not going to be able to do a transplant, and he's going to have to have three negative blood cultures before they would even consider...(Wife P5, First Interview, Day 5)	

Strategy	Exemplar Quotes	Response
<b>Neg_Say that Patient Can't Hear:</b> FM described the nurse telling the FM that an unresponsive patient is unable to hear	We always just come in and get right down in his ear and say, 'Hey how are you? We're here.' He/she [nurse] was around the corner, he/she came up and said, 'he can't hear you.' And I'm like, 'well I don't care if he can hear me or not, I'm still going to talk to him.' 'Well he can't hear you.' Oh, it pissed me off. I don't care whether he can hear me or not, if I'm, if I want to talk to him, I should..., don't come in here and tell me he can't hear me. I don't care whether or not he can hear me, it makes me feel better, you know? And I have actually even thought of asking the charge nurse to change him to someone else because that doesn't leave you a good feeling...I go to bed feeling agitated. (Wife of P11, First Interview, Day 4)	Dissatisfied
<b>Neg_Tell FM This Is All Normal:</b> FM described the nurse saying that what was happening was all normal.	It was more in the context of, "this is all normal," well no this is not normal to us. You know, "this is all perfectly normal." This is not normal to us....This is like far from normal. This is the opposite end of normal. Or what I'm doing is normal. Or that's normal. I don't know. (Wife of P3, First Interview, Day 2)	Difficulty Coping, Dissatisfied
<b>Validate FMs Love and Concern for Patient:</b> FM described the nurse has validating the FM's love and concern for the patient.	He/she let me know how serious her condition was; he/she didn't sugar coat anything; he/she kept saying 'don't beat yourself over this' and letting me know how good of a daughter I was and how I stood by mama's side. (Daughter of P15, Third Interview, Day 14)	Accept, Personal Connection, Trust
<b>Psychosocial:</b> FM described behaviors that supported the family members' coping and ability to maintain an intact family unit		



Strategy	Exemplar Quotes	Response
<b>Allow FM to Stay During Procedures:</b> FM described the nurse allowing the FM to stay during procedures.	They actually let me stay during the bath, which I really probably never would choose to do again, just because of his condition when he's moved to a certain-particularly the right side because that's where most of his pneumonia and the fluid is-his number's really go bad, and it's like a very tense to me and frightening, and I think they were just doing it so I could have more time in there, but given my druthers, I probably wouldn't want to witness that again. I'd rather step out for fifteen minutes than see that. (Wife of P17, Second Interview, Day 9)	Difficulty Coping
<b>Allow FM to Stay During Procedures</b>	I mean because when [nurse] was here the whole twelve hours of the day, when he/she was here, he/she don't really stress me about having to leave out the room or like whenever she comes, if he/she is doing any kind of care or taking blood cultures and that kind of thing. [Nurse] don't let me leave the room; he/she let me stay right there because that's my mama. So he/she will close the curtain and leave me back there with her. (Daughter of P15, Third Interview, Day 14)	Trust, Cope

Strategy	Exemplar Quotes	Response
<b>Assess Social Situation:</b> FM described the nurse asking about the social situation at home.	He/she asked a lot of questions that probably weren't on the paper, about our situation at home, "do you care for him by yourself, is there someone else there that's with you? How do you feel about that? Are you stressed at all? Do you think you might want help when you go home?" It was more than just, "when was his last chest x-ray." It was more than, and maybe there are psychosocial questions on there that he/she has to ask, but it seemed like he/she was truly interested in getting the whole picture... It's important, I think, that [the nurse] sees that there is more to it than just, "this is the person who gets the discharge instructions and goes to the pharmacy and picks up the prescriptions and anything else." ....Well they always ask questions. For instance, when we initially came here and he/she said, after going through, "are you alone? Does anybody live with you, who do you live with? Then you are responsible for his care. You are the sole care giver. Do you feel like you are stressed? Do you feel like you need help? Would you be open to having help at home?" That kind of interest in, "what's going to happen when this family is ready to go? Are they going to be well supported, and have we addressed everyone's concerns here." Not just, "well he's stable now. (Wife of P1, Single Interview, Day 2)	Trust, Comfortable Asking Questions
<b>Bend the Rules:</b> FM described the nurse being willing to bend the rules about visiting hours when the situation warrants.	They are gracious about allowing more than two people to be in there, and I'm not sure they do that for everybody, but I think in certain conditions and patients they probably do allow it and don't get flustered by it. And also I think if we are not having a wild party in there, they probably don't care...And they are just very thoughtful about the things that they can do that will make us feel comfortable and make us feel that we are not just room number 3. (Wife of P1, Single Interview, Day 2)	Personal Connection, Confident, Trust

Strategy	Exemplar Quotes	Response
<b>Bend the Rules</b>	I know that there is a rule that there is only two visitors in there, but for me and both kids to be able to be in the room at the same time and not have to separate us as a family, just bending those rules a little bit here and there means a lot so we can be there together... It helped me be with my kids...for their support because they are 20 and 23, and they are looking at losing their dad, and they are really struggling... We need to be together as a family right now, and that allows us to be there. (Wife of P11, First Interview, Day 4)	Cope
<b>Encourage FM to Participate in Care:</b> The FM described the nurse encouraging them to participate in the care of the patient.	And he/she even asked me to help him/her move mama and put the pillows behind her to help her position and stuff. (Daughter of P15, Third Interview, Day 14)	Trust
<b>Encourage FM to Take Care of Themselves:</b> FM described the nurse emphasizing that the FM needs to take care of him/herself, including encouraging FM to get enough sleep, talk about feelings, cry, and use coping mechanisms.	But [nurse] told me, 'you've got to go home. You've been here two days, you've got to go home and get you some rest.' And he/she was good at that. He/she was like, 'you've got to take care of yourself, and I know that. I'm a social worker, I know you have to take care of yourself...'I knew he/she was very concerned about me...I felt that. (Wife of P11, First Interview, Day 4)	Trust
<b>Encourage FM to Take Care of Themselves</b>	'Take care of yourself because you are going to have to take care of him when he goes home.' That's nice. It kind of makes me think, Oh good!. But it doesn't change the reality, but it's nice. They, I say the most hopeful thing is, 'you have to be healthy yourself to take care of him.' And that was a nice thing to say, but it wasn't like, you, 'you're going to take him home tomorrow so you better have a good dinner tonight.' It wasn't that kind of optimism. And I think that's good, that's professional to me. (Domestic Partner of P8, Single Interview, Day 9)	Trust

Strategy	Exemplar Quotes	Response
<b>Encourage FM to Take Care of Themselves</b>	And he/she explained to us, and I knew I needed to do it, and we were trying, but I really needed to concentrate on rest and food for us...And he/she just reassured us to go get some rest and food...Yeah take care of myself, take care of us...Good. Very nice. Yeah, yeah. I mean I knew it, and I was working, I was working towards that, getting that routine. (Wife of P3, First Interview, Day 2)	Cope
<b>Explain That Patient Can Hear:</b> FM described the nurse explaining that, although the patient might not be responding, the patient might be able to hear what the FM is saying.	[The nurse] didn't kill it because my mother said, he heard me, he heard me. The nurse said, 'yeah, a lot of times they can hear you talking, so say all you need to say to him. Say it in his ear, talk to him.' So, he/she very gently said, 'well just keep talking to him and encourage him.' It was one of those things, and it helped. It helped her instantly. I saw it because she thought, 'my grandson heard me,' and she did not know at the moment whether it would be the only time she would get to say what she needed to say to him. Do you know? And hopefully he did hear her, and I'm hoping he did. But that's important because...if you lose somebody right after that, that's going to help you be okay with it. Not okay, but be able to say, 'I said what I needed to say and they heard me.' (Mother of P10, Single Interview, Day 2)	Able to Cope, Closure
<b>Go beyond Regular Duties:</b> FM described the nurse being willing to go beyond what is required to do extra things to assure that the patient and FM have what they need.	Yeah and another time...we had wanted to come back, and they were doing something, and they said 'come back in a few minutes.' Well instead of waiting for us to come back [the nurse] actually came all the way out to where we sit and was like 'I want to come get you because...I know visiting hours will be up in a little while, and I wanted you to be able to come back before that ended.' And I thought that was nice too. I mean, I just think some of that stuff is kind of, they don't have to do that stuff, it's nice, so I just felt like they're kind of going beyond what they have to do. (Granddaughter of P14, Single Interview, Day 6)	Trust, Cope

Strategy	Exemplar Quotes	Response
<b>Use Personal Story to Encourage Coping Behavior:</b> FM described the nurse using a personal story to encourage the FM to use coping behaviors	<p>One nurse did say, I think I started crying, and he/she said, "That's going to make you feel better," or something like that, "I know the feeling, I'm a nurse now, but I've been in a situation, not exactly the same, and I always felt better when I cried." ...but when he/she said that, it just made me feel like it was a personal, a person coming just for our family. He/she didn't have to share that. And he/she didn't share details didn't share where it was, but he/she just said something like that, just to say that, don't feel, go ahead and cry. (Sister-in-law of P2, single Interview, Day 2)</p>	Cope, Trust
<b>Encourage Coping Behavior</b>	<p>I started crying, and [the nurse] said, "I know the feeling, I'm a nurse now, but I've been in a situation, not exactly the same, and I always felt better when I cried." Something like that. I'm paraphrasing somewhat, and I can't remember whether that was on the regular floor or the ICU. And he/she was really there to do all the tubes and things, but when he/she said that, it just made me feel like it was a personal, a person coming just for our family.(Sister-in-law of P2, Single Interview, Day 2)</p>	Trust, Personal Connection, Cope
<b>Neg_Rigid:</b> FM described the nurse as rigid about rules.	<p>[That nurse] sticks right by the rules; two people, he/she doesn't bend the rules any. And we'd both like to see him/her just relax. It's just the two of us, we're not bothering anybody, we're not loud, we just want to sit with him. But he/she, she kicks us out, 'you got to go.' ...We want to be with him. I mean if our time is limited, we want to be with him every minute we can be with him. And he/she knows how critically ill he is. So, I don't know, I guess some people are just more stickler for the rules...I would like to, just like right now, I don't have anywhere to go, anything to do for two and a half hours, why can't I sit there quietly on my lap top? He's not going anywhere, he's not getting any, you know, nothing major's going on with him. I just want to be there. But, I can't. (Wife of P11, Third Interview, Day 12)</p>	Dissatisfied, Difficulty Coping, Lack of Trust and Confidence
<b>Spiritual:</b> FM described behaviors that supported spiritual well-being		

Strategy	Exemplar Quotes	Response
<b>Acknowledge Faith:</b> FM described the nurse demonstrating an understanding that their faith is important to them and respect for that faith.	<p>Even when Claude came in, we had gotten a prayer cloth that we wanted to put a blanket over him, [the nurse] explained that that was fine but that also his temperature had been going up that's why the room was so cool so it may be removed. But he/she honored her request to put it over him and understood that...From my experience I understand the medical side of things, but I also believe in the spiritual side that God Almighty has the last say so....It's more of 'I can relate.' ...Even when the nurse came to tell what my father had done he/she also made the comment 'continue to pray,' so that lets me know that you too know the powers that God has as well and that prayer can change things... It makes you feel good because I think one of the biggest things that we've always heard is that faith, and the determination of the patient can also go a long way. (Daughter of P12, First Interview, Day 3)</p>	<p>Hope, Trust, Confident</p>

### **4.4.3 Approach: Build Rapport**

Family members described strategies that strengthened the therapeutic relationship. These strategies included holding the family members in high esteem, being approachable, and being affable. These strategies helped the family members to feel a personal connection with the nurse, to trust that the nurse cared about them as individuals, and to feel confident that the patient was receiving quality patient care. This rapport fostered coping by allowing the family members leave the ICU at the end of the day confident that their loved one was in competent, caring hands.

#### **4.4.3.1 High Esteem**

Family members described behaviors that demonstrated that the nurse held them in high esteem, valued them as people, and did not judge them. These behaviors included reassuring the family member that no question is “ignorant,” telling the family member that the nurse liked them, and showing an interest in the family member’s and patient’s background and interests. One family member told how much it meant to him that the nurse asked him to bring in pictures of his wife so that the nurses could know what she was like before she became unresponsive. Another family member described the nurse asking about what her grandmother was like:

And [the nurse] asked about Memaw, like ‘what does she like to do’ and that kind of thing. [It was] personal, Memaw just wasn’t just a patient. It’s like [this nurse] wanted to get to know her. I just felt like they care. That made me feel good about him/her taking care of her. It’s like he/she wants to know this about

her that he/she cares enough to ask, then I know he/she's going to take good care of her... Well it's hard to leave, but it makes it easier to leave knowing that they're going to be taking care of her...(Granddaughter of P14, Single Interview, Day 6)

Holding the patient and family member in high esteem helped the family members to feel confident in the care, to trust the nurse, and to cope with the challenges of having a critically ill loved one.

Two family members described behaviors that demonstrated lack of esteem. One related that the nursing staff questioned why he was not visiting more often. The other described a nurse being very condescending:

It's the way [the nurse] talks to you, really talks down. 'Ma'am I told you, this is.' [This nurse] will repeat him/herself like, 'are you not getting what I'm telling you?' And it's just the way he/she talks, and I don't care for that at all. So, we don't care for that at all. So, I go to bed kind of agitated myself. [The nurse was] very condescending on the phone last night when I called, like I was bothering him/her...or like it was a bother. Like if he [patient] was agitated, it was going to be a bother. (Wife of P11, Second Interview, Day 8)

This negative communication led to dissatisfaction, feeling judged, and lack of trust.

#### **4.4.3.2 Approachable**

Family members described the nurses welcoming them into the patient's room by introducing themselves, encouraging the family members to ask questions, and encouraging them to call any time if they had questions or if they needed reassurance that their loved one was stable. Family members also described nurses being willing to



take time with family members and to be patient with the needs of both family members and patients. Another strategy that family members described was a willingness to admit mistakes and apologize. These strategies helped the family members to cope, to feel comfortable asking questions, and to trust that the nurse would be there for them.

An important aspect of trust in the nurse was the nurses' willingness to engage with the family member by making eye contact, facing the person, and talking directly to them. The husband of a patient with end stage cancer expressed this willingness to engage:

They've been super open .... I have no problem asking them, or feel like I'm interrupting them...It seems like I get the sense that talking to the family is part of their job, and they take it, they do that, just like they do anything else; they devote their attention to it, their full attention. Yeah I mean it's not like they're doing other stuff. I mean they might be doing other stuff while talking to you, but a lot of them just take time just to sort of, not sit down with you but stand there with you and look you in the eye and talk to you directly, as opposed to sort of while they're doing something else or...(Husband of 4, First interview, Day 2)

Family members expressed that the nurses' willingness to engage increased their confidence in the care and their ability to cope.

Although the family members reported mostly very positive experiences with nurses engaging with them, in three cases the family members described encountering a nurse who did not seem to be engaged with the family. The behaviors they identified included looking at the computer and not making eye contact, turning their back to the

family member, and not introducing themselves when the family member entered the room. The daughter of a patient described her experience with one such nurse:

And normally at shift change, you'll get the hug or the care from the one leaving and the invitation that, 'everything's going to be okay' from the one coming on board. And at this shift change I got the care and concern from the one leaving, and from the one coming on board, wouldn't even look me in the eye. And if you don't look a person in the eye...I did not want to leave, I was like 'dear Lord please I've got to leave this place, and I don't want to leave it.'...When I left, there was no eye contact, there was no attempt to shake my hand, not even turn the chair in my way. So he's here with the nurse, I'm leaving so there was-it was like, 'you can just head on out of here I'm not even concerned with you.' There was no attempt to pull me in to his/her world. I just...every radar in me went up, this is not good. This is not good...no you don't sleep. (Daughter1 of 13, Second interview, Day 8)

Family members described experiencing difficulty coping, lack of trust and confidence in care, hesitancy to ask questions, anger, and dissatisfaction in response to nurses whom they perceived as not engaging with them.

In a few cases, the family member perceived that the nurse was curt, dismissive, or blunt, and thus did not feel a personal connection and did not describe the nurse as approachable. A family member, who overall was very pleased with the nursing care, reported being very distressed over the behavior of one particular nurse on the night shift whom she perceived as curt:

I said 'hi' and called this person's name, and I said 'how's my dad doing,' and the response I got was exactly this 'well the same as any other day, the same as any other day.' I'm like 'you sorry sack of shit, I want to drive to [name of hospital] right now; my dad is going to get in trouble overnight.' So the fact that he had to be intubated that morning does not surprise me at all. Oh I wanted to

get in the car-I prayed because I knew it was out of my hands, and it was in the hands of somebody less than competent, and it made me feel extremely vulnerable and helpless, as someone who cares about that patient laying in the bed, vulnerable and helpless...(Daughter1 of P13, Second Interview, Day 8)

The consequences of negative behaviors such as these were dissatisfaction, hesitancy to ask questions, difficulty coping, and lack of trust and confidence.

#### **4.4.3.3 Affable**

Several family members described nurses as being patient, personable, engaging in small talk, using humor, and sharing personal stories, which helped the family member feel connected.

It's friendly, I mean they are all very friendly. I guess you would say personable, the small talk type stuff. When they are in the room, they would ask us, about what are we doing, if we were students, where we were from, what we are studying, so forth, small talk, personable... Again, it was a relief, refreshing...I guess it made me feel closer to the staff, more like friends instead of whatever technical word we are. I guess friends, yeah, friendship. (Son2 of P3, Single Interview, Day 2)

Physical closeness and touch were described as strategies that helped to develop personal connection and trust between family members and nurses. Several family members described how much they appreciated a hug from a nurse or physician, and one family member described nurses as "the warm blanket" in an otherwise cold environment.

When family members described nurses using strategies to build rapport, such

as being affable and approachable and expressing esteem for the family members, they expressed confidence in the patient care, trust that the nurse cared about the family, and better ability to cope. Several family members expressed that they were able to go home and rest and sleep knowing that their loved one was in competent, caring hands. Several family members reported difficulty coping and lack of trust and confidence when they perceived that the nurse caring for their loved one did not attempt to build rapport.

Table 10: Approach: Build Rapport

Strategy	Exemplar Quotes	Response
<b>Demonstrate High Esteem:</b> FM described behaviors demonstrating that the nurse held the patient and FM in high esteem		
<b>Affirm:</b> FM described the nurse being accepting of them and showing positive regard toward them. Example is saying, "that is a great question" or "no question is stupid."	Yeah, and it's important to me too because I'm not a doctor or nurse; sometimes it sounds like an ignorant question, and they assure me that it isn't. I've had...almost every question I've asked someone will say, 'well that's an excellent question,' whether it is or not. (Son of P14, Single Interview, Day 5)	Trust, Comfortable Asking Questions
<b>Affirm:</b>	He/she was with her for a couple of nights, and it was one point when we went back there, and I don't know if somebody didn't come in or if they got more patients or what, but anyway, he/she was asked if he/she wanted to change patients or something maybe and not be with [patient], and he/she told them 'no' that he/she wanted to stay where he/she was; he/she liked the family; he/she wanted to stay involved, so we were glad. And I said 'I'm so glad you did that because we would miss you if you went away,' so I just think a lot of him/her; he/she's good. All of them are good, but he/she has been really good... Yeah I mean we were glad to hear that, that he/she wanted to stay with her and see her through. (Daughter-in-law of P14, Single Interview, Day 6)	

Strategy	Exemplar Quotes	Response
<b>Encourage FM to talk about Patient:</b> FM described the nurse encouraging the FM to talk about the patient, might include showing pictures of the patient.	And [the nurse] asked about Memaw, like ‘what does she like to do’ and that kind of thing. [It was] personal, Memaw just wasn’t just a patient. It’s like [this nurse] wanted to get to know her. I just felt like they care. That made me feel good about him/her taking care of her. It’s like he/she wants to know this about her that he/she cares enough to ask, then I know he/she’s going to take good care of her... Well it’s hard to leave, but it makes it easier to leave knowing that they’re going to be taking care of her and that they have our numbers and they’ll call you know if they need us for anything. (Granddaughter of P14, Single Interview, Day 6)	Cope, Confident, Cope, Personal Connection
<b>Encourage FM to talk about Patient</b>	Phone call from 401. He said they asked for pictures of his wife to hang up because they wanted to see what she was like before she got this sick. He said he felt that they saw her as a person, not just a body lying in the bed. Looking at the pictures led to discussions about her and about where the pictures were taken and what was going on then. It gave him a sense of having a personal connection with the nurse and also that the nurse understood her better. He felt that the nurses may give her better care if they knew her as a person rather than as a mute person lying there. (Husband of P4, Phone call, Day 8)	Confident, Personal Connection
<b>Encourage FM to talk about Patient</b>	I could just see the care. I could see that he/she cared; he/she talked to me, and we showed him/her pictures of my mom before all of this. And my brother even likes him/her-and my brother don’t like nobody, so. <<laughter>>My brother like you, then you alright so. (Daughter of P15, Third Interview, Day 14)	Trust, Confident

Strategy	Exemplar Quotes	Response
<b>Neg_Ask Why FM Not Visiting More Often</b>	Some friends have called in, they're like "where's the family how come the family's not here" I'm like well we're far away we can't always be here...I was a little annoyed because it's like well we're there as much as we can be there but we can't be there twenty four hours a day. And it was Thanksgiving besides I mean I had to get my daughter home, because she, you know, it doesn't do her a whole lot of good to be here... I don't know why the nurse would say that..., but we're here as much as we can and frankly, I'm not sure what good it would do for us to, why they would say that because what difference would it make? If they need to do something they have my cell phone number, they can call me just like they did with the gallbladder. So there's no reason to be here other than... just to, unless [patient] wakes up...But uh, when she's asleep, which she's been for a week, there really is nothing you can do except visit for your- it's more just for myself you know? [Patient name] doesn't even know we're there, so I really uh, I don't know why we need, why the nurse would say, "where's the family." (Husband of P4, Second Interview, Day 7)	Feel Judged, Dissatisfied
<b>Neg_Condescending:</b> FM described the nurse talking down to them or communicating in a disrespectful manner	It's the way [the nurse] talks to you, he/she really talks down. 'Ma'am I told you, this is.' [This nurse] will repeat him/herself like, 'are you not getting what I'm telling you?' And it's just the way he/she talks, and I don't care for that at all. So, we don't care for that at all. So, I go to bed kind of agitated myself. [The nurse was] very condescending on the phone last night when I called, like I was bothering him/her...or like it was a bother. Like if he [patient] was agitated, it was going to be a bother to him/her. (Wife of P11, Second Interview, Day 8)	Lack of Trust and Confidence, Difficulty Coping, Afraid to Ask Questions, Dissatisfied
<b>Be Approachable:</b> The FM described the nurses being open and warm in their interactions.		

Strategy	Exemplar Quotes	Response
<b>Acknowledge FM:</b> FM described the nurse acknowledging their presence by introducing themselves to the FM when the FM arrives or by nodding or saying hello when the nurse sees the FM in the hallway.	Yes he/she introduced him/herself immediately, explained what had been going on during the day and asked me if I had any questions. Very people-person, hands on. He/She was taking blood work and writing down numbers and checking his/her machines-first thing he/she introduced him/herself. I was made to feel comfortable immediately. (Friend of P6, Single Interview, Day 2)	Cope
<b>Encourage to Ask Questions and Call:</b> FM described the nurse being open to the FM asking questions and encouraging FM to ask questions and call anytime.	They told me that I could call anytime they give me my information that I need. Anything that I ask they try to answer, and if they think they can't, they find somebody that can. They get the doctor for me if I need to talk to them. They've been great; anything that I ask they try to answer. Well they talk to me when I first come in, and 'if you got any questions you please let me know.' Oh it makes you feel good. At least they will answer your questions! [laughs] because there have been some places in the hospital, and they don't want to talk to you about nothing. Okay, I'm still okay because they said 'call me anytime, twenty four seven;' they say, 'if you call we'll talk to you.' I woke up like two o'clock in the morning, and I called, and I talked to the nurse. So that's good, that's amazing to me that they can talk to you, talk to you and not...don't mind you know? And like I said they said that 'if you wake up just call if you want to, we here and we awake.' I said 'well that's a good thing!' [laughs]. But they said that they would call if they think I needed to be called so...that makes me feel better because I know that if something did happen to happen, they would call me...it makes me feel better. And like I said, if I do want to call, I can call, regardless of whether they had called me or not. (Mother of P16, Single Interview, Day 4)	Cope, Comfortable Asking Questions, Trust



Strategy	Exemplar Quotes	Response
<b>Listen, Hear with Thoughtful Attention:</b> The FM described the nurse giving the FM full attention. Includes looking FM in the eye.	They've been super open .... really personable, and I can't, I have no problem asking them, or feel like I'm interrupting them or they have taken time away from things they need to do. It seems like I get the sense that talking to the family is part of their job, and they take it, they do that, just like they do anything else; they devote their attention to it, their full attention. Yeah I mean it's not like they're doing other stuff. I mean they might be doing other stuff while talking to you, but a lot of them just take time just to sort of, not sit down with you but stand there with you and look you in the eye and talk to you directly, as opposed to sort of while they're doing something else or...(Husband of P4, Second Interview, Day 7)	Comfortable Asking Questions, Trust
<b>Listen, Hear with Thoughtful Attention</b>	And so they let us know, and if they hear us talking about something like 'I wonder why this is like this, I wonder why that's like that,' and they'll turn, and I'll say 'why'. They'll turn towards me to say, I'm going to give you... Like eye contact I can explain it if you want me to. (Sister of P9, First Interview, Day 3)	
<b>Patience:</b> FM described the nurse demonstrating patience with the FM and with the patient.	It was "okay what do you need," and they explain, even if they had to explain it five times to me because I just couldn't hear, I couldn't think, you know? Nobody acted agitated, or irritated, or no bad bedside manner, it was none of that, and it's so important because you are so raw right then, your nerves, there, any little thing can set you off...And I'm sure that there might be a time up here that these nurses wanted to say, 'oh please sit down and we will come to you in just a second,' but they don't do that. They haven't with us so far. You find yourself buzzing, you don't mean to, but you go, 'can I come back now or can I,' it's because you're sitting there waiting. And, and you would think that they probably think, 'please quit hitting that buzzer, I told you we can't do that right now.' But, no they never were short, or...important, very important. (Mother of P10, Single Interview, Day 2)	Trust, Cope

Strategy	Exemplar Quotes	Response
<b>Patience</b>	When we needed them they were there, and he pushes that call whenever he may, and when he was upstairs they, no matter what when they did he, and I know you're talking about ICU, but what I'm trying to say is they did, and this is when he was alert and was able to do it himself, it didn't seem to bother, agitate or upset them that he's pushing it. And if they could come, if they could come to see what he wanted, if they couldn't do anything right then they'd say 'well we'll be back.' And he may push it again before they get a chance two or three times, but never did they act as if they were upset with him doing it. (Wife of P12, First Interview, Day 3)	Confident
<b>Willing to Admit Mistakes:</b> FM described the nurse apologizing after the FM expressed discontent about a behavior.	But I would have appreciated the nurse calling to let me know that he had done that... Yeah, he/she didn't call and let me know. But I still would have wanted to know... I'll put it this way, if we felt that in any way he wasn't getting the proper care, we would not go home at night. We would stay right out here in that waiting room... I know, I guess he/she didn't want to disturb me or anything. But I have felt good that I haven't got any calls during the night. But now that I would have wanted to know. So...I talked with him/her about it, and he/she apologized, he/she just didn't want to disturb us because they knew they had to, they would put it back in, and that was something that we told them to do. (Wife of P12, Third Interview, Day 17)	Trust
<b>Willing to Admit Mistakes</b>	And he/she just kind of assured me that he/she wouldn't do anything to hurt her, and he/she was like, he/she was really sorry if he/she came off kind of strong or if he/she came off like his/her attitude was not 'for us' or whatever, so he/she apologized, but I still keep that thought in the back of my mind. (Daughter of P15, Third Interview, Day 14)	

Strategy	Exemplar Quotes	Response
<p><b>Willing to Engage:</b> FM described the nurse being available and willing to interact with FM. Includes behaviors such as making eye contact, introducing self, facing the FM, taking time, and drawing FM into conversations</p>	<p>Just the level of care that she's getting. ..the night nurse was just very, seemed very, caring and just ready to answer all questions and stop whatever he/she was doing to answer questions. And the same with [nurse2]. They don't seem, it's not like you're bothering them. They seem awfully willing and able to answer the questions and stop whatever they're doing and just take time to answer your questions because there are a lot of questions with her condition, obviously. So just made sure we understood what was going on.. it's just comforting to know that there's, that they, there is somebody there that is just looking out for them constantly. And just...on top of that so you don't have to really worry about them. You know they're getting best care possible...Yeah I'm very impressed with both [nurses]... they seemed just so calm and professional and just very soothing to talk to... they definitely know what they're doing. ..they just seemed to have a good bedside manner, I guess. They're not gruff or seem to be annoyed by your questions or anything. It's just, they're willing to answer anything and take as much time as you need to understand what it is you need to understand. (Husband of P4, First Interview, Day 2)</p>	<p>Confident, Cope</p>
<p><b>Willing to Engage</b></p>	<p>They are just animated. They will talk and engaged, they are engage, they engage you. They are concerned. Even though they know... the outcome might not be good, but they are still very engaged. And that's helpful to me. And I feel like he's being taken care of the best that he can. (Domestic Partner of P8, Single Interview, Day 9)</p>	<p>Confident, Cope</p>

Strategy	Exemplar Quotes	Response
<b>Negative_Avoid Engaging:</b> FM described the nurse as ignoring or avoiding them. Specific behaviors included: avoid eye contact, fail to ask if FM has questions, and fail to offer explanations.	Just sort of the nonchalant, 'well everything's the same.' That, it's kind of like, I will just wait until the night-nurse comes on...I think body language has a lot to do with it...The ones that just sort of stand there without... You don't feel like you are engaging. It's like, do you understand what I'm asking you?...So, I guess it's sort of a stiffness or whatever, which would probably be, or no body reaction would probably be the biggest clue to me that I'm not sure that I'm getting through with my questions. (Domestic Partner of P8, Single Interview, Day 9)	Afraid to Ask Questions
<b>Negative_Avoid Engaging</b>	But I didn't feel like I could ask him/her questions...When I...was back there, visiting Memaw, when he/she kind of sat at the computer, he/she was the only one that didn't really speak when I walked into the room. He/she never came into the room when I was in there. But he/she was the only one that didn't offer any information...I felt the vibe he/she was giving off was that he/she didn't want to be bothered, that kind of thing...he/she didn't really make eye contact, he/she didn't acknowledge that we were coming, that we were back there. He/she didn't say anything to us, so...(Granddaughter of P14, Single Interview, Day 6)	Dissatisfied, Lack of Trust and Confidence

Strategy	Exemplar Quotes	Response
<b>Negative_Avoid Engaging</b>	And normally at shift change, you'll get the hug or the care from the one leaving and the invitation that, 'everything's going to be okay' from the one coming on board. And at this shift change I got the care and concern from the one leaving, and from the one coming on board wouldn't even look me in the eye. And if you don't look a person in the eye...I did not want to leave, I was like 'dear Lord please I've got to leave this place, and I don't want to leave it'...When I left, there was no eye contact, there was no attempt to shake my hand, not even turn the chair in my way. So he's here with the nurse, I'm leaving so there was-it was like, 'you can just head on out of here I'm not even concerned with you.' There was no attempt to pull me in to his/her world. I just...every radar in me went up, this is not good. This is not good...no you don't sleep. (Daughter1 of P13, Second Interview, Day 8)	Difficulty Coping, Lack of Trust and Confidence.
<b>Neg_Curt/Short:</b> FM described the nurse giving short answers to questions without explaining	I said 'hi' and called this person's name, and I said 'how's my dad doing,' and the response I got was exactly this 'well the same as any other day, the same as any other day.' I'm like 'you sorry sack of shit, I want to drive to [name of hospital] right now; my dad is going to get in trouble overnight.' So the fact that he had to be intubated that morning does not surprise me at all. Oh I wanted to get in the car-I prayed because I knew it was out of my hands and it was in the hands of somebody less than competent, and it made me feel extremely vulnerable and helpless as someone who cares about that patient laying in the bed, vulnerable and helpless...(Daughter1 of P13, Second Interview, Day 8)	Difficulty Coping, Lack of Trust and Confidence

Strategy	Exemplar Quotes	Response
<b>Neg_Dismissive of Concerns:</b> FM described the nurse failing to acknowledge the importance of the FM's feelings or concerns.	<p>And while we were back there, the whole time we were back there, she [patient] never blinked; her eyes were just wide open, and she wasn't blinking...so when we left the room, I asked the nurse, I said, 'I noticed she's not blinking her eyes at all.' I said, 'do you put anything in them?' because it seemed like they would just get dry or whatever; you need to blink every now and then. And I said 'do you put anything in them to keep them, like you know moist, wet, something to make them not get irritated,' and he/she answered and said 'well she closes them every now and then.' And I thought, 'okay thank you.' [Granddaughter laughs]. So he/she didn't really answer, he/she gave me an answer but didn't really answer my question-didn't answer my question, so I just didn't ask him/her anything else. [Laughs] (Daughter-in-law of P14, Single Interview, Day 6)</p>	
<b>Neg_Impatient:</b> FM described the nurse as impatient with the FM or patient	<p>Well like the nurse, the nurse that I was asking the questions to, you could tell he/she was real agitated, and I kept asking him/her questions, and he/she wanted me to leave the room all the time. (Daughter of P15, First Interview, Day 2)</p>	<p>Afraid to Ask Questions</p>
<b>Neg_Impatient</b>	<p>And then yesterday, as soon as [the nurse] got here, he [patient] was squirming like this, he/she said, 'we got to have some of that, we can't have him squirming like that.' Nobody else has had that reaction to him. They are like, 'okay he is a little agitated.' 'Well we just can't have that.' And that's when it's time to leave at night, and I'm like, 'do I really want to leave him?' And I have actually even thought of asking the charge nurse to change him to someone else because that doesn't leave you a good feeling, it doesn't me. Not good. (Wife of P11, Second Interview, Day 8)</p>	<p>Lack of Trust and Confidence, Difficulty Coping, Afraid to Ask Questions, Dissatisfied</p>
<b>Be Affable:</b> The FM describes the nurse as friendly, open, and engaging		

Strategy	Exemplar Quotes	Response
<b>Personable:</b> FM described the nurse as warm, kind, compassionate, helpful, friendly, and personable, "people person." "nice and polite and pleasant."	They are all very friendly when I walk back there. They all, I mean they don't know me, but they all speak as if it matters that I'm coming through. 'Hi, how you doing? And if there is anything we can do for you, be sure and let us know.' And that's very, I think that's important to people... I feel like I wouldn't hesitate if I needed them for something, to ask. (Sister of P5, First Interview, Day 5)	Trust, Comfortable Asking Questions
<b>Physical Touch/Closeness:</b> FM described the nurse using physical touch or closeness.	The nurses are the warm blanket, standing there and rubbing you and hearing their voices. The doctors come in and they do, and the doctors are good too, but they don't...the nurses make all the difference. Nurses can make your stay comfortable or they can make it uncomfortable. (Sister-in-law of P2, Single Interview, Day 2)	Trust
<b>Physical Touch/Closeness:</b>	I'll tell you this...twice... I know it happened twice that the nurse that was in charge of the unit said 'I think you need a hug.' And I was not...I was just, I was just standing there. So it wasn't one of those things where I was all over the floor crying and hootin' and a hollerin', and he/she did, he/she said 'I think you deserve a hug.' Twice it happened. And I think things like that are just as important as that needle you're putting in, when they get to a bad shape. When they get to the...[showing ]that they're people and that you're people, that you're not just something, you're not stuffed animal. That sounded ugly didn't it? You can get a stuffed teddy bear and set it anywhere, and he don't know what's going on but you have feelings don't you? And...if it's somebody that you love. Instead of just walking on by me and going on by what he/she needed to do to the next patient he/she said 'I think you deserve, need a hug.' [And that showed] compassion and that he/she cared. (Sister of P5, Second Interview, Day 13)	Trust

Strategy	Exemplar Quotes	Response
<b>Physical Touch/Closeness:</b>	And you know being an only child and trying to face this all day long most days by myself, I need that, I need those nurses to care. I need those doctors to care, and I need those doctors to care about me because most of the day, I don't have that family support to grab a hold of. And I know that if I need to go back there and cry, somebody's going to hug my neck. You know? (Son of P14, Single Interview, Day 5)	Cope, Trust
<b>Physical Touch/Closeness:</b>	They're up and close, they just want you to, um, they're just up close and personal; it's that personal space that you generally only get with people that you know that I've noticed that nurses do here; they're in your personal space, so to speak, when they're asking you questions; it's not from the hall or...That makes me feel like I'm not a bother. (Sister-in-law of P2, Single Interview, Day 2)	Comfortable Asking Questions, Trust
<b>Small Talk:</b> FM described the nurse talking to the FM about things not related to medical/nursing care, such as where they are from, things in common, such as love of animals, etc.	It's friendly, I mean they are all very friendly. I guess you would say personable, the small talk type stuff. When they are in the room, they would ask us, about what are we doing, if we were students, where we were from, what we are studying, so forth, small talk, personable... Again, it was a relief, refreshing...I guess it made me feel closer to the staff, more like friends instead of whatever technical word we are. I guess friends, yeah, friendship. (Son2 of P3, Single Interview, Day 2)	Personal Connection



Strategy	Exemplar Quotes	Response
<b>Small Talk</b>	Having someone like nurse L. makes you sleep a little easier at night when you leave here, makes walking out the door at night easier. I think his/her background was so similar to my background and my sisters' background. We all grew up playing sports, he/she went to [school] ...there's just something about him/her. He/She's compassionate, and I felt that from him/her from the moment I met him/her; there was a warmth...and a truly caring, I really felt that daddy just wasn't his/her patient; it was someone that he/she had connected with and cared about. (Daughter2 and Daughter3 of P13, Third Interview, Day 11)	Trust, Confident
<b>Use Humor:</b> FM described the nurse using humor in a way that is positive	And the nurses kind of like...that side of things because you'll hear them chuckle, or they'll say something to him 'did you hear what she said' or something like that... I mean they don't carry it on, but they do lighten the load some. I like that, see to me, I like that. I don't want everything to be doom and gloom... I never feel stressed, I never feel tight, I never feel anxiety or anything when I'm in there. (Sister of P9, First Interview, Day 3)	Trust, Cope.

#### **4.4.4 Approach: Demonstrate Professionalism**

Family members described behaviors that they perceived as demonstrating professionalism, including a professional demeanor, the perception that the nurse was carrying out his/her role and acting within his/her scope of practice, evidence that the nurse was collaborating with physician colleagues and with other nurses, and demonstrations of respect. (See Table 11) Family members responded to these strategies by feeling confident in the care, trusting the nurse, and being better able to cope. Unprofessional behaviors and indications of lack of collaboration were associated with difficulty coping and lack of trust and confidence.

##### **4.4.4.1. Demeanor**

The nurses' demeanor was identified by many family members as important to their ability to feel confident in the care. Several family members described nurses having a calm presence that was reassuring. An example of this comes from the husband of a patient with advanced cancer:

Just seeing how good they are has made me more hopeful. Yeah I would say that I don't know if hope is quite the right word. It's maybe more...sort of relaxed or accepting kind of just um... just more comfortable knowing she, that she's here in good hands and everything... It was just...their calm demeanor and their grasp of the facts... it wasn't like they had to go ask somebody. They knew, they just explained things clearly and um...right off the top of their head. With just a, just in a very calm reassuring way. (Husband of P4, First Interview, Day 2)

This participant indicated that the demeanor of the nurse made him feel more hopeful

and confident that his wife was getting excellent care. Other participants indicated that the confidence they had in the nurse helped them to cope and to be able to rest and sleep at night.

Family members described nurses behaving in ways that demonstrated positive morale, professional work ethic, and a sense of a higher duty to the patient and family member. Specific behaviors included expressing an enjoyment of their work, being alert to the patient's needs, not complaining about their work load, and not openly engaging in non-work related "chatter" outside the patient's room. These behaviors helped the family members to cope better, to feel confident in the nursing care, and to trust that the nurses would be there for them and for their family member. Some family members described behavior that demonstrated a lack of professional ethics, such as chatting about non work related issues and not paying attention to the patient's needs, which resulted in difficulty coping and lack of trust and confidence.

#### **4.4.4.2 Role and Scope of Practice**

Several family members described how much comfort they received knowing that a role of the ICU nurse was to be an abiding presence, watching over their loved one. Observing how attentive the nurses were and knowing that the nurse would be outside of the patient's room watching every move gave family members a great deal of comfort. Two family members expressed anxiety when their loved one was discharged

from the ICU, believing that their loved one would not get the same level of care and observation. Family members also appreciated that nurses enacted their role by being able to be objective observers and not injecting the nurse's own personal issues into the care of the patient and family.

Several family members expressed their expectations of scope of practice of an ICU nurse concerning the delivery of prognostic information and discussion of EOL decisions. Family members rarely described nurses directly imparting prognostic information. A few described having asked a nurse for a prognosis and the nurse saying that he/she could not give that information. Only one family member described a nurse saying that the patient would die, and this was after she had directly asked the nurse when he/she thought the patient would die. Several family members expressed an expectation that the prognosis would be delivered by the physician, after which the nurse might discuss the prognosis. When asked about the nurses giving prognostic information, some family members expressed appreciation that nurses did not interject their "personal" opinion. One family member described her experience and expectations thusly:

They're very professional. They don't cross the line; they tell you what they can tell you, and they tell you as much as they can tell you, but I have not seen where they elaborate; I've not seen where they've given their opinions. I've only seen...that they honestly give you the medical side of things. It's never their opinion, their feeling. It's never how they think; it's never what they would do; it's never any of that, and I like that. I agree with staying professional, and

they've done that. They've not ever said 'well if it was my family member' or 'I can tell you right now it doesn't seem like he's going to make it,' they never do that. They are very careful in how they talk to you.

In a later interview, this same family member described the nurse discussing EOL decisions only after the physician had discussed these decisions with the family member:

The nurses talked to me about that [morphine drip]. Not as in depth as the doctor, but once they knew I knew about it, they would always say, 'I'm giving him morphine to keep him comfortable,' but once they knew I had spoken to the doctor about it, they talked a little bit more about it then, about the drip versus the other. And when I would ask a question, yesterday when decisions were being made, they would say 'you know what that's something you really need to ask the doctor; if you would like for me to get the doctor I will.' I thought that was good because they don't want to answer something that's out of their lane. (Sister of 9, Second interview, Day 5)

Very few family members were able to recall a nurse initiating discussions of prognosis. With one exception, the few participants who recalled having any discussions about prognosis with nurses described the nurses avoiding the topic of prognosis until the physician had brought it up, deferring to the physician in these discussions, avoiding injecting a "personal opinion." The participant who elaborated the most on this topic indicated that she expected the nurse to avoid giving a "personal opinion" about what should be done and to avoid injecting the nurse's own opinion about the prognosis. This participant expressed satisfaction with care and ability to trust the nurses. The sole participant who did receive direct information about the prognosis had

asked the nurse directly when her family member might die. She was told that he would likely die that night or in the morning.

She described her favorable perception of this strategy:

I was in there sometime there by myself, I said, 'Nathan, I want you to know how much I love you, and I want to tell you how much I want to appreciate you accepting me as your sister.' It could have been, well, she's not, she's not really ours, but that was never the case...[The nurse] told me it could be tonight or early in the morning. And I appreciate that...I said, 'can you tell me,' and he/she said, 'tonight or in the morning.' ... I think it's important with anybody to have that [closure] don't you? I think that's why some people can't get over death, sudden death, family deaths if they have not had that. They've either not had the closure or they've got some guilt feelings. And I've got both. I mean, I think I did my closure thing when I told him thank you for accepting me. And I loved him. I think he could see it. And I think I can accept it. (Sister of 5, First interview, Day 5)

#### **4.4.4.3 Collaboration**

Family members described evidence of collaboration among members of the health care team, which instilled confidence in the care of the patient and trust that the information they received was consistent and truthful. Several family members described the nurses working together as a team, helping each other for the greater good of the care of the patient:

Yes, [nurse R] who was his nurse yesterday; it was busy on the floor yesterday, you could tell it. As a family member, you're dealing with what's in your room, but you knew it was a busy, busy day on the floor. And [nurse R] and all the nurses [named several nurses], they were all checking in, 'what do you need, how can I help you?' It was a really team effort yesterday on that floor, and you could sense.... Fantastic, phenomenal, compassionate, caring, clinically astute

nurses! They're all interacting and helping one another... And here, the nurses are much more confident; it seems like there's much more interaction both nurse to nurse, there are examples yesterday especially with [nurse R], who is still a relatively new nurse, was fantastic. But it was like the mother hens. I said, 'you've got mother hens too.' Because [nurse S] was in, [names several nurses]... They were mother henning him/her because I think what happened at shift change, here [nurse R] walks in to this difficult situation with my father, and it rattles you, and you've got eleven more hours of this. So it was like his/her mother hens surrounded him/her, and they're helping him/her and all of that stuff. (Daughter1 of P13, Second Interview, Day 8)

Family members also described collaboration between nurses and physicians.

Indications of this inter-professional collaboration included the nurse expressing confidence in the plan and the nurse paging or asking the physician if the nurse was unsure about something. The daughters of one patient described seeing the nurse interact with the physician on rounds:

Daughter2: It's good interaction between the doctors coming through and [the nurse], and it just, it makes you feel good.

Daughter1: Yeah, and there was a time it was [nurse L], when the attending was rounding with the residents..., and [nurse L] interjected and didn't hold back from that. What they exchanged was [nurse L] interjecting whatever it was... information, and then a confirmation of what [nurse L] had said...

Daughter1: For me it was like, 'these people have their ducks in a row, and if anything happens to my father, I truly believe that he was at the best place, and he is getting the best care.'

D2: It made me feel that they're not dropping the ball because they're not communicating...At least they're working as a team to try and help our father.

D1: Coordinated. (Daughter1 and Daughter2 of P13, Second Interview, Day 8)

The participants expressed that evidence of collaboration helped them to have hope and gave them confidence in the care.

Three family members described inconsistency in the information that they received from the physician versus the nurse. Although all three stated that this inconsistency led to confusion about what was really happening, they also expressed confidence in the nurse, and two indicated that they trusted the information from the nurse more than the information from the physician.

Granddaughter: So we've had at least one time I know the doctor actually told us something wrong, and we thought it was wrong, and so I told him [patient's son], "ask the nurse"...One was telling us one thing, and one was telling the other, and so we asked the nurse, who was with her all the time, and got-'cause we were confused we were like 'wait a minute.'

Daughter-in-law: Mhm, it's like [granddaughter] said, they're the ones back there with her. I mean the doctor comes around and checks, but they've got other surgeries to do, I suppose, and other patients, but that nurse is with her from beginning the shift to end of shift, so they're the ones knowing what's going on. (Granddaughter and Daughter-in-law of P14, Single Interview, Day 6)

#### **4.4.4.4 Respect**

Family members described the nurses enacting their professional role by demonstrating respect for the confidentiality and dignity of the patient. Several family members expressed appreciation for nurses who demonstrated respect for the family member by treating them with courtesy and politeness. The friend of a patient with dementia expressed his appreciation that the nurses treated the patient with respect and dignity:

And we had to fuss at him to make him put his pull ups on, and we'd go out to eat and sometimes he'd you know, whew [holds his nose], and but nobody ever said a word, especially up here in the hospital up here...It's part of their job.



(Friend of P6, Single Interview, Day 2)

Respect for the patients and family members led to increased trust in the nurse, reassurance that the patient would receive quality personalized care, and increased ability to cope.

Family members described various strategies that demonstrated professionalism. These included a having professional demeanor, carrying out their professional role, acting within their scope of practice, collaborating with nurse and physician colleagues, and demonstrating respect. With one exception, family members were clear in their belief that delivering prognostic information was the role of the physician.

**Table 11: Approach: Demonstrate Professionalism**

Strategy	Exemplar Quotes	Response
<b>Demeanor:</b> FM described the nurse's demeanor as demonstrating professionalism		
<b>Calm Presence:</b> FM described the nurse as calm in the face of a crisis or difficult situation.	He/she's calm, well-informed, has a lot of experience, anything you ask him/her he/she's more than happy to answer and explain. That's pretty much... especially when you're, most people, I'm sure family members, that are not in there are calm... [It made me feel] a lot more comfortable with everything, I guess, able to deal with things; it seems, it's easier. (Wife of P5, Second Interview, Day 6)	Able to Cope, Trust in Nurse, Confident in Care
<b>Confident and Competent:</b> FM described behaviors that demonstrate the nurse are competent and confident	I think when I am talking to a nurse, and he/she is explaining what's going on and can tell me, and especially with the kids, this is what that means, and this is what's going on, this and that. I just feel very comfortable that they, they feel comfortable in what they are doing. They know what to do if the blood pressure, I mean obviously there is a resident on board and that sort of thing, but they pretty much work on their own, and I feel confident that they know what they are doing. And I'm specifically talking about the surgical ward now, all of them, what they're doing. But when it's this kind of intensity, and there is a lot going on, a lot can go wrong real quickly. I feel that they are on top of things. (Domestic Partner of P14, Single Interview, Day 9)	Confident in Care, Able to Cope

Strategy	Exemplar Quotes	Response
<b>Confident and Competent:</b>	[The nurse] just started moving, moving, moving, moving, moving. He/she knew exactly what to do. He/she was just knew what steps to take. And it seemed like some of the other ones have had to ask a little more. They had a little more help; he/she didn't need a lot of people helping him/her. People were always offering, and when he/she needed it he/she took it. He/she just knew his/her job. It made me feel like he/she knew what he/she was doing, because there have been times it's like, 'they don't know what they're doing,' you know? He/she had no doubt, in his/her mind, he/she knew what he/she was doing. So that confidence level...I had confidence in him/her. I was able to see that he/she knew what he/she was doing and that gave me a lot of comfort that this person is working on my husband knows his/her stuff. (Wife of P11, First Interview, Day 4)	Confident in Care, Able to Cope
<b>Confident and Competent</b>	I guess the main thing for me though is knowing that they are intelligent, they are informed, they know what they are doing. So, watching them do their thing, and doing it well is one of the things that make, that helps me open up. Open up to them...confidence in their ability and their intelligence...And they are all very professional. Very professional. And I like that. (Son1 of P3, Single Interview, Day 2)	Comfortable Asking Questions, Confident in Care
<b>Confident and Competent</b>	Just seeing how good they are has made me more hopeful. Yeah I would say that I don't know if hope is quite the right word. It's maybe more...sort of relaxed or accepting kind of just um... just more comfortable knowing she, that she's here in good hands and everything... It was just their, it was just their demeanor and their calm demeanor and their grasp of the facts... it wasn't like they had to go ask somebody. They knew, they just explained things clearly and um...right off the top of their head. With just a, just in a very calm reassuring way. (Husband of P4, First Interview, Day 2)	Hope, Confident in Care

Strategy	Exemplar Quotes	Response
<b>Morale:</b> FM described nurse demonstrating positive morale and work ethic.	And that made a difference to me because if you are doing something that you don't want to do, a person can tell, and he/she didn't seem that way. He/she seemed to be glad and happy to do what it was that he/she was doing. Yeah, yeah he/she really did, the way he/she was talking and explaining it. And he/she was talking to my mother at the same time, and that made me feel better because that showed me that okay he/she's going to do what he/she is supposed to do as far as being a nurse. And some don't. Yeah, yeah. It did, it makes a difference when you are here, even if it wasn't as serious as it is, it still makes a difference in how the nurse acts when she comes into a room. And he/she made me feel better...And it makes a difference if you're talking to someone that act like they don't want to talk to you. And he/she didn't sound like that, I don't know who he/she was yesterday morning, but he/she didn't sound that way. Yeah it makes a difference, it will make me feel like, 'well they ain't going to do what they're supposed to be doing, or even half of what they are because they don't want to tell you so they don't want to what they're supposed to be doing.' I feel like if you're going to do or take care of the people you need to be...if you're going to...nursing is not a job it's an occupation. And you have to want to do what you're doing and do it the way you're supposed to be doing it. Because you can't just go on and say, 'I'm going to take your temperature,' and you don't have nothing to say? And he/she talked the whole while we was in there; so that makes a difference. That makes, to me it does. (Daughter of P7, Single Interview, Day 2)	Able to Cope, Confident in Care
<b>Professional Ethics:</b> FM described the nurse having a sense of higher duty to the patient/FM	It's never they get so tied up with us that they don't; they forget what they're doing. I've seen that happen and I haven't seen that here. They really do treat this as if it's ICU. And you know what, I feel that the nurses treat me as if I'm just as important as the patient, and the patient is just as important as the doctors and the other nurses. (Sister of P9, First Interview, Day 3)	Confident, Trust

Strategy	Exemplar Quotes	Response
<b>Professional Ethics</b>	What I am seeing when I walk through there, are people that are concerned and are attentive and very on the job. And sometimes there have been other places or other environments where there's, I mean I'm all for people being happy and laughing, my husband's a big joker and laugher, but given the nature of this, it's kind of, like I said it's not like it's a death march or anything like that, but it's more just like, people seriously being attentive and following up with what's happening very quickly. And I find that very reassuring. Kind of having their finger on the pulse, I guess. (Wife of P17, First Interview, Day 3)	Confident
<b>Unprofessional Behavior:</b> FM described behavior that demonstrated lack of professional ethics.	And she's turned her back talking to the nurse next door. And I am, my anxiety and temper went out the roof. Really, all of the other nurses have kept their eyes on him. And she's got her back, and I'm watching the clock twenty minutes later they're still chit-chatting about transfers, job openings, this that and the other. (Daughter 2 of P13, Second Interview, Day 8)	Lack of Trust and Confidence, Difficulty Coping
<b>Role/Scope:</b> FM described the nurses acting out their role.		
<b>Abiding Presence:</b> FM described the nurse being present and watching over the patient.	I slept very well last night and my reason for that is because I trust the people that are in there. I know that he is in good hands, I know that. I trust the care he is getting in there. I know if anything goes wrong, anything goes wrong they will call me immediately, and I will be able to get in here to and be there. So, I sleep very well when I leave here at night because I trust the care, I trust the nurses, I trust the physicians. I know he is being observed and any little twitch is going to cause someone to stop and look at him. So, I am very comfortable with that. Call me crazy, but that's very important because if you can leave and go home and feel like that, then you can be refreshed to come back the next day and do the things that you have to do to be the supportive person there with the patient. And absorb all the information you are supposed to be taking out with you and taking home with you. (Wife of P1, Single Interview, Day 2)	Cope, Confident

Strategy	Exemplar Quotes	Response
<b>Abiding Presence</b>	Wife: I can understand as far as the doctor, doctor's going to come examine, then they have to go to the next patient. But the nurse is going to be there...And I know sometimes with the doctor, the doctor gonna have to just have to tell you what's going on, and the nurse is there, and they're going-they're re-emphasizing what the doctor is saying, but they're putting a little um... Daughter: More compassion. (Wife and Daughter of P12, First Interview, Day 3)	
<b>Ask About Baseline:</b> The FM described the nurse asking the FM about the patient's baseline behaviors or status.	The new nurse came on duty before I left last night, and said, "do you have just a few minutes before you go," and he/she asked um...what were the particular signs of his agitation. And he/she said, "please explain what I should be looking for, what is his normal way? What are you experiencing with him, when you're with him." ...And I [said], "well he scratches his head all the time and is forever scratching and licking his moustache. And that's when he's aggravated, the meal hasn't gotten there fast enough, or he's in a hurry to go somewhere, and you'll see that behavior." But he/she was concerned about what to look for. And I was impressed with that, he/she wasn't just saying "well he's here, and I'm going to take care of him with what I see, I'm going to go a little bit further." ...Definitely involved with what was going on, and I felt like he was more comfortable because if he/she's a step ahead of him that's good... He/she was going to follow through. (Friend of P6, Single Interview, Day 2)	Confident
<b>Cognizant of Scope of Practice:</b> The FM described the nurse being cognizant of the appropriate role and not overstepping the bounds of his/her profession	But the nurse will not, they will not, and I made a mistake in asking the nurse that, but he/she made it clear that that's something the doctor... But a nurse will never answer that question, I've noticed. And I've noticed it's probably because they're not supposed to be doing that. They always say, "that's something I can't answer. The doctor, though, I can page the doctor for you." They'll page right away, within three minutes, they call back. "I can page the doctor or go get the doctor or leave a note for the doctor, but I can't answer that." (Sister-in-law of P2, Single Interview, Day 2)	

Strategy	Exemplar Quotes	Response
<b>Cognizant of Scope of Practice</b>	No they're always very optimistic. They kind of leave that up to the physicians, and..."that's not my place to say that." ...But I'm sure they would defer to the doctor. Unless the doctor had told them to tell me. That's what I would think that they would do... some things they'll defer-they'll defer to the physician on other things. It's like we're not-a nurse has been there fifty two years, and is an RN, but he/she will not tell me anything unless the doctor tells them to. You know how doctors are; they're gods; my daddy thought they were, and my mama. (Friend of P6, Single Interview, Day 2)	
<b>Cognizant of Scope of Practice</b>	The nurses talked to me about that. Not as in depth as the doctor, but once they knew I knew about it, um they would always say, 'I'm giving him morphine to keep him comfortable,' but once they knew I had spoken to the doctor about it, they talked a little bit more about it then, about the drip versus the other. And when I would ask a question, yesterday when decisions were being made, they would say 'you know what that's something you really need to ask the doctor if you would like for me to get the doctor I will.' I thought that was good because they don't want to answer something that's out of their lane. (Sister of P9, second Interview, Day 5)	Cope, Confident
<b>Objective:</b> FM described the nurse being able to be objective.	But...I think they ride that fine line of not getting too... interacting with their personal experiences. Which kind of in a way I appreciate because, even though you feel for their past experiences, I think they're uh...more educated to help you with what you're going through at your time of need. (Daughter2 of P13, Second Interview, Day 8)	Trust
<b>Collaboration:</b> The FM described evidence that the nurses were collaborating with other professionals.		

Strategy	Exemplar Quotes	Response
<b>Express Confidence in Plan:</b> The FM described the nurse expressing confidence in the plan	<p>That he is getting good care, oh yeah, that he's getting good care and that this is just not like, something enormously experimental, or that this is not a shot in the dark, this is not a wing and a prayer. You know what I'm talking about. That this is almost sort of the way they handle this situation. [Confidence] in what the doctors are doing. Yeah and maybe give some explanation of, not we do this all the time, it's that, you know like, their number one in the protocol to do this, but, I don't know, maybe everybody is not, could not understand, could not understand that, don't even know what the word protocol means. Somehow say that, not we do it all the time in a flippant manner, but we are very good at doing this type of treatment or therapy...[Relieved] that he is getting good care and that this is just not like, something enormously experimental, or that this is not a shot in the dark, this is not a wing and a prayer. (Wife of P3, Second Interview, Day 4)</p>	
<b>Inter-professional Collaboration:</b> FM described evidence of collaboration between the nurse and his/her 7physician colleagues	<p>And I also noticed that, how can I put it? A couple of times one of the nurses was looking at his numbers and everything, and I saw him/her, and he/she went to the doctor, was talking to the doctor and got him and came back and had him to see what was going on because there was a doctor there. And one time, one of the nurses talked with the nurse, the charge nurse and didn't hesitate to get help if they needed it. (Wife of P12, First Interview, Day 3)</p>	



Strategy	Exemplar Quotes	Response
<b>Interprofessional Collaboration</b>	D1: I also believe very respectfully, that its nurse to doctor too here... I truly believe if they saw something, they would question one of the residents or the fellows, and they would say 'well what about this?' I'm sure they would do it quietly and respectfully, but I do believe that that interaction is going on... D2: It's good interaction between the doctors coming through and [the nurse], and it just, it makes you feel good. D1: Yeah, and there was a time it was [nurse L], when the attending was rounding with the residents, and [nurse L] interjected and...didn't hold back from that...What they exchanged was [nurse L] interjecting whatever it was... information, and then a confirmation of what [nurse L.] had said...D1: For me it was like, 'these people have their ducks in a row, and if anything happens to my father, I truly believe that he was at the best place, and he is getting the best care.' D2: It made me feel that they're not dropping the ball because they're not communicating...At least they're working as a team to try and help our father. D1: Coordinated. (Daughter1 and Daughter2 of P13, Second Interview, Day 8)	Confident, Cope

Strategy	Exemplar Quotes	Response
<b>Intraprofessional Collaboration:</b> FM described evidence of collaboration among nurse colleagues.	<p>Yes, [nurse R] who was his nurse yesterday; it was busy on the floor yesterday, you could tell it. As a family member, you're dealing with what's in your room, but you knew it was a busy, busy day on the floor. And [nurse R] and all the nurses [named several nurses], they were all checking in, 'what do you need, how can I help you?' It was a really team effort yesterday on that floor, and you could sense.... Fantastic, phenomenal, compassionate, caring, clinically astute nurses! They're all interacting and helping one another... And here, the nurses are much more confident; it seems like there's much more interaction both nurse to nurse, there are examples yesterday especially with [nurse R], who is still a relatively new nurse; he/she was fantastic. But it was like the mother hens. I said, 'you've got mother hens too.' Because [nurse S] was in, [names several nurses]... They were mother henning him/her because I think what happened at shift change, here [nurse R] walks in to this difficult situation with my father, and it rattles you, and you've got eleven more hours of this. So it was like his/her mother hens surrounded him/her, and they're helping him/her and all of that stuff. (Daughter1 of P13, Second Interview, Day 8)</p>	<p>Confident</p>
<b>Neg_Inconsistent Information:</b> FM described receiving information that is inconsistent, either from one person or from one professional to another	<p>There was a huge debate about whether or not to remove his breathing tube amongst the whole staff, I mean... the nurse could see that he was coming to more and more and struggling with it being in there without any kind of sedation or anything. And yet he was also obviously still just very weak... [The nurse] went to speak to them; he/she was like, 'I really think that it might be time because they'd reverse themselves; they told me they were going to do it, and then when I got, I called at like eight, I call every morning around eight or eight thirty, and they said, 'no we think he's a little too weak.' Well then his levels are getting so high, they couldn't keep even the machine was down to the lowest settings, but he's obviously breathing really well, and so they, I just think the nurse just really paid close attention to his numbers and um...(Wife of P17, Second Interview, Day 9)</p>	<p>Uninformed, Difficulty Coping</p>

Strategy	Exemplar Quotes	Response
<b>Neg_Inconsistent Information</b>	Granddaughter: So we've had at least one time I know the doctor actually told us something wrong, and we thought it was wrong, and so I told him [patient's son], "ask the nurse"...One was telling us one thing, and one was telling the other, and so we asked the nurse, who was with her all the time, and got-'cause we were confused we were like 'wait a minute.' Daughter-in-law: Mhm, it's like [granddaughter] said, they're the ones back there with her. I mean the doctor comes around and checks, but they've got other surgeries to do, I suppose, and other patients, but that nurse is with her from beginning the shift to end of shift, so they're the ones knowing what's going on. (Granddaughter and Daughter-in-law of P14, Single Interview, Day 6)	Difficulty Coping, Uninformed
<b>Respect:</b> FM described nurse demonstrating respect for the patient and family		
<b>Confidentiality:</b> FM described the nurse's efforts to maintain patient's confidentiality	It's been very nice, and even though they know that I know his diagnosis, and they know I know where things are going, they are still very careful when they are changing shifts. They talk among themselves, and I can hear them, but they still are very private in transferring things over where they want to be mindful of his ear as well as my ear. And so I thought that was very nice, even though I'm sitting there and all that but they still are very engaged and professional in changing things over so I thought that was very nice. (Sister of P9, Second Interview, Day 5)	
<b>Respectful:</b> FM described nurse treating the FM with courtesy and politeness, as if they are an important part of the team, and being respectful of cultural and religious differences.	I feel that the nurses treat me as if I'm just as important as the patient, and the patient is just as important as the doctors and the other nurses. (Sister of P9, First Interview, Day 3)	Cope

Strategy	Exemplar Quotes	Response
<b>Respectful</b>	They've talked to me...like I am a person that...that's important to them...Yes, and so that makes me feel good that they...the caring part really helps you when you're in a situation like this, so it's very much so that they...talk to me and all that kind of thing really helps me. And I'm a talker anyway; I like for people to talk to me, and it helps me to deal with stuff and that kind of thing so. (Mother of P16, Single Interview, Day 4)	Cope
<b>Respect Patient Dignity:</b> FM described the nurse being respectful of the patient's dignity	And we had to fuss at him to make him put his pull ups on, and we'd go out to eat and sometimes he'd you know, whew [holds his nose], and but nobody ever said a word, especially up here in the hospital up here...It's part of their job. (Friend of P6, Single Interview, Day 2)	Confident

#### **4.4.5 Approach: Provide Factual Information**

Family members described nurses as an important source of information. Family members were helped by receiving factual information about the ICU environment, equipment, and treatments as well as factual information about physiological findings. In addition, family members appreciated being kept apprised of the changes in the condition. When family members perceived that nurses were unable to answer their questions, gave vague answers, gave inaccurate information, or failed to keep them apprised of changes, they expressed difficulty coping and lack of trust and confidence in the nurse. (See Table 12).

##### **4.4.5.1 Descriptions of environment, equipment, and treatments**

Family members described nurses providing information and answering questions honestly using lay terminology. They expressed that having the nurses explain what was happening helped them to cope better because they felt they understood what was happening and at times felt more prepared for what might happen next. Having a nurse who was able to provide detailed information about what he/she was doing and why inspired confidence in the ability of the nurse to care for the patient and instilled trust that the nurse would be there for the family to help the family understand what was happening as evidenced in this remark from a family member:

I think when I am talking to a nurse, and he/she is explaining what's going on and can tell me... this is what that means, and this is what's going on, this and

that. I just feel very comfortable that they, they feel comfortable in what they are doing. They know what to do if the blood pressure, I mean obviously there is a resident on board and that sort of thing, but they pretty much work on their own, and I feel confident that they know what they are doing. (Domestic Partner of P8, Single Interview, Day 9)

Some family members remarked how much they appreciated nurses who were able to anticipate that the family member might have a question or were able to sense that the family member had a question and would answer it without having to be asked.

An example comes from a young man who was visiting his father:

If I sat there for too long or if I looked puzzled or something [the nurse] would usually come and explain whatever it was that I was looking at or would ask if I had any questions. And he/she was kind of clever about how he/she asked if we were figuring things out for ourselves to see, to get us to, I guess to tell him/her any questions we had, instead of asking if we had any question, which I thought it was clever... Well I was glad that he/she was interested in what we thought...But when they do ask, I always feel like it's a relief that they are involving us and keeping us informed. It definitely makes this, makes this whole process easier. (Son of 3, Single interview, Day 2)

The ability of the nurse to anticipate the family member's needs helped them to cope and further enhanced the trusting relationship between the family member and the nurse.

#### **4.4.5.2 Description of patient findings**

Family members described nurses updating them about the condition of the patient by recounting the objective findings, such as the patient's movements, need for ventilator support, blood pressure, other vital signs, and laboratory values. Several

family members indicated that they relied on this factual information to draw their own conclusions about the prognosis. Although several family members expressed that they wanted honest information, did not want things “sugar coated,” and did not want nurses to give them false hope, many also indicated that they did not want to be told that their loved one was dying or “not going to make it.” Several family members indicated that, even though they knew the prognosis was poor, they particularly appreciated when the nurses pointed out positive findings, even when these were very minor changes, citing the need for some “glimmer of hope.”

Well any time that they tell me that a number looks better, that's hopeful. His ammonia level was 13 points better today. And I went 'oh, that was a little glimmer of hope. He's not on any sedation, but yet we are getting a little bit of response. That's a little bit of hope.' Just little things like that. (Wife of 11, first interview, day 4).

Family members trusted that the nurses would keep them apprised of any changes in the condition of the patient and would call them or come talk to them in the waiting room to tell them if there were any significant changes. Although they appreciated how busy the nurses were, having a nurse come to the phone when the family member called in for an update was crucial to their ability to cope. Being told to call back later was described as excruciating for some as they wondered what was happening to their loved one. Some were told to wait only to have someone call back later and say they were tied up with another patient. They expressed that they would

have appreciated being told that the nurse was busy with another patient, so that they would not wonder if their loved one was in grave danger.

Although most often the family members found the nurses to be informative and forthcoming with information, in a few instances the family members described strategies that blocked information, such as being unable to answer questions, giving vague answers, guessing at what might be wrong, and giving inaccurate information. The family members responded to these strategies by expressing a lack of confidence and trust in that nurse and feeling that the family member lacked the information needed to understand the situation and make decisions. One family member described her response to being given inaccurate information:

Some will say, 'well nothing's changed since last night,' and then I will find out, yes he did have a seizure, ...well that to me is important to know in the overall scheme of things. So, I'm thinking that he didn't have a seizure for two days, when actually he did have one the day before, that sort of thing. (Domestic Partner of P8, Single Interview, Day 9).

Family members relied on nurses to keep them informed. When family members described nurses anticipating their need for information, providing explanations, and keeping them apprised of changes, they expressed being able to cope, to have confidence that the nurse was competent, and to trust that the nurse would keep them informed. Several family members described the excruciating anxiety they experienced when they called and were told to call back in 30 minutes. Family members also



reported lack of confidence, difficulty coping, and difficulty making decisions when they were given inaccurate information or experienced a nurse who gave vague answers to questions or were unable or unwilling to answer questions.

Table 12: Approach: Provide Factual Information

Strategy	Exemplar Quotes	Response
<b>Explain Environment:</b> FM described the nurse giving explanations of the equipment and procedures.		
<b>Answer Questions</b>	[The nurse] was excellent; he/she answered any questions that we had, and I told him/her, I said ‘we don’t want to interfere with your care of him, but I don’t know, I’m not a medical person, so I don’t know’ and he/she explained everything to my satisfaction...It helps you to understand what’s going on with him and to know how to react to some of this. (Wife of P13, First Interview, Day 3)	Understanding of Condition, Trust, Prepared
<b>Answer Questions</b>	I’ve asked a lot of questions just about; I remember asking questions about the feeding tube and, what else did I ask about? I don’t know, one day I just had kind of a list of questions, everything I saw on her that I didn’t know what it was or what it was doing, I asked about, and the nurse that day was really...it’s like you said before, I didn’t feel like he/she was rushing me; I didn’t feel like he/she was trying to get through my questions so he/she could do something else. He/she took his/her time and explained everything. And...some of them know that I’m a nurse, but they...used layman’s terms and explained it well. Because sometimes you ask questions, and they tell you the answer, and you still don’t know what they meant. But they were really, really good with their answers, and it cleared up any kind of confusion I had, so I don’t think I asked any questions that they, that I still didn’t know the answer to when I left. (Granddaughter of P14, Single Interview, Day 6)	Trust, Informed

Strategy	Exemplar Quotes	Response
<b>Explain Equipment:</b> FM described the nurse explaining what equipment is used for and what alarms and numbers mean.	It is very helpful because when you've got twenty bags hanging, and they're over there doing something, which bag are they working on, which number are they working on, and even one went as far to explain what the mean score was for his pressure, and I thought that was awesome because I wouldn't have ever known. I saw it on the monitor, but I wouldn't have ever known. But it's very helpful to a family member, at least to me, because it's helpful to know what's going on. You see that the person is very sick, critically ill, which is what ICU stands for, Intensive Care Unit. (Sister of P9, First Interview, Day 3)	Informed
<b>Explain Equipment</b>	I think when I am talking to a nurse, and he/she is explaining what's going on and can tell me, and especially with the kids, this is what that means, and this is what's going on, this and that. I just feel very comfortable that they, they feel comfortable in what they are doing. They know what to do if the blood pressure, I mean obviously there is a resident on board and that sort of thing, but they pretty much work on their own, and I feel confident that they know what they are doing. (Domestic Partner of P8, Single Interview, Day 9)	Confident

Strategy	Exemplar Quotes	Response
<b>Explain Equipment</b>	<p>[The nurse] did explain to me when he came in his oxygen level was one hundred percent. We saw the PEEP scale or the PEEP number; he/she told me that twelve was high. They wanted him to come down some gradually; they would wean him down. It wasn't just that we were just looking at the oxygen because the PEEP was important too because that's the pressure. So we understood that a little bit more and were able to, okay well we come in here we're going to look at this too. Even this morning the nurse who is on duty now, even went a little bit further; he/she told us about the green letter 'C' and how that means that he's been assisted. However they may change to an 'S', where he's doing it on his own. Just informative, giving you information. I looked at his vitals; I knew yesterday they-one nurse asked, 'well let me explain what that temperature means' because it wasn't in Fahrenheit and, Celsius I would assume, that it needed to be around thirty six, so we needed to look for thirty six versus a thirty seven and a thirty eight... they took the time to let us know what was going on and why they're doing this and just learning, and we knew what to look for. So when we came in and one time his temperature was thirty eight point five, and we knew they were hoping it to get to thirty six, and a couple of times we came in, and that's what it was. But when we came in that day, and it was thirty eight, and then another time it was thirty seven, well we knew that his temperature was coming down because they had already explained all that to us. (Daughter of P12, First Interview, Day 3)</p>	Trust

Strategy	Exemplar Quotes	Response
<b>Explain Equipment</b>	Well I think another great example of that is today when [nurse L] had answered all the questions we had, and then said 'well the doctor will be in at you know, or 'rounding later;' I can't remember his/her exact terms, but 'the doctor, if you have any questions you'll be able to ask the doctor,'... And then mom and I looked at each other and go, 'you got anything else?' I'm good...We felt like way informed. Now I'm sure the doctor could say something about the x-ray or da-da-da, but for us it, was kind of like 'you've got anything else?' mom goes 'no,' and that sense of 'wow I'm good' (Daughter1 of P13, First Interview, Day 3)	Trust
<b>Explain the Plan:</b> The FM perceives that the nurse explains what the plan is for the patient's treatment for that day, including contingency plans	One thing I do like is sort of, especially when they tell me, when they provide me with an update or status. And then also explaining if something does or doesn't work or what the next step may or may not be because then I can have a realistic expectation instead of getting my hopes up like, 'oh well were making progress and were going to be here, going to be there.' You know what I mean, instead of being realistic about what could happen. (Wife of P17, First Interview, Day 3)	Prepared, Cope.
<b>Use Lay Terminology:</b> FM described the nurse using terminology that the FM is able to understand when explaining things to the FM	It relieves some of the stress that you have, I believe that a lot of stress comes from either families not understanding things, being afraid to ask about big words that they may not understand. I do find that the team up here will give you the medical names for stuff, but they will also break it down for you in layman's terms. I love that. Because we don't understand those terms, but they seem to break it down in layman's terms. They'll say 'belly' they'll say you know 'something's in the belly or the bowel,' and they let us know what's going on like that in layman's terms. (Sister of P9, First Interview, Day 3)	Cope, Informed

Strategy	Exemplar Quotes	Response
<b>Use Lay Terminology</b>	D1: Yes whether it's the doctors or the nurses. And I even said one time, here's another example, as they finished rounding the attending said 'feel free to ask any questions,' and this was another time that [nurse L] was on with us. And I said I'm okay, [Nurse L]'s here; I know that he/she'll be that bridge to me. He/she understands what you guys are all talking about, and he/she's the one that's going to bring it down to the kindergarten terms that I need. I don't want to waste your time with that. And I felt confident and comfortable that [nurse L] was competent in translating that to my terms. D2: It makes you more comfortable about what's going on. D1: Yeah [nurse L] is the communicator bridge; he/she understands the ten dollar lingo. I don't get it; it's all confusing to me. But when they walked away, I knew that I could pepper him/her with questions, and he/she would give everything I needed on my terms. (Daughter1 and Daughter2 of P13, Second Interview, Day 8)	Confident
<b>Present Patient Findings:</b> FM described the nurse describing physiological findings, such as vital signs, laboratory tests, and ventilator settings.		
<b>Avoid Rendering a Prognosis:</b> The FM described the nurse giving factual information without giving an opinion about the patient's life expectancy or prognosis	So, they've tried to explain things to me that I don't understand...and it's helpful to know that he's only getting this tiny bit of support, that he's initiating the breaths. So, that tells me that maybe the ventilator is not doing everything; that he is...still has some control. So, that was helpful to know...If I don't understand the lab results or something, they will explain those. That is helpful to me. Those kinds of things... I have to say, they are, they will tell you what they know, but as far as any kind of personal opinion, they don't really give a lot of personal opinions, they give more, my questions are more probably, I don't know if you want to say, scientific? But, 'what does this do; what does this mean; what does this lab test show; what does that effect?' Those kinds of things, and they explain because I'm not a nurse, so I want to know what that correlates to. So they are very helpful at answering those kind of technical questions. (Wife of P11, Third Interview, Day 12)	Hope, Informed, Cope

Strategy	Exemplar Quotes	Response
<b>Avoid Rendering a Prognosis</b>	Well it's a glimmer of hope, but they are not so, 'oh no he's not going to make it,' or 'I've never seen anybody come through this.' Just, if they've got that opinion, they are not saying it, so that I can hold on to that glimmer of hope. (Wife of P11, Second Interview, Day 8)	Hope
<b>Describe Positive Patient Findings</b>	Well any time that they tell me that a number looks better, that's hopeful. You know? His ammonia level was just like 13 points better today. And I went oh, well that was a little glimmer of hope. He's not on any sedation, but yet we are getting a little bit of response. That's a little bit of hope. Just little things like that, that. (Wife of P11, First Interview, Day 4)	Hope
<b>Describe Positive Patient Findings</b>	We see a hundred of those setbacks and jump forwards in an hour.' And they reassured me that a couple of little step backs doesn't mean that an hour from now there's not going to be a leap forward. And they've pointed out the positive stuff to me. And that's been important to me. 'Cause if I go back and see one thing that doesn't look right, I say 'oh my God,' but then they say 'look at this right here, look how much this has improved; this is better.' They share lab results with me and stuff like that and the fact that her kidneys had stopped and now they're doing great, stuff like that. 'We've taken her off both blood pressure medicines.' So they keep reinforcing my hope with doing that, with pointing out the positive stuff. And it is important to have hope, and like I said, I've got tremendous faith; my mom has tremendous faith, so we're going to be okay if she doesn't make it. But it's still important to have that hope that she is, and the nurses and the doctors keep giving me that, so it's extremely important. (Son of P14, Single Interview, Day 5)	Hope, Cope

Strategy	Exemplar Quotes	Response
<b>Keep Apprised of Condition:</b> FM described the nurse keeping them apprised of any changes in the condition of the patient, including calling them at home, going out to the waiting room when there is a change, or not leaving the FM hanging when they call.	Knowing that people care about you, you know? And knowing that I'm sitting out there, wondering what's going on, and if something is getting ready to happen or whatever, they come out there and get me you know? And stuff like that. They don't have to do that, so it makes me feel really good to be here and that my mom's here... I know that if anything significant happens, they're going to call me. (Son of P14, Single Interview, Day 5)	Trust, Cope, Informed
<b>Keep Apprised of Condition</b>	And even the one time the nurse was busy, he/she didn't say ... "Tell them I'll call them back." What happens then is that if he/she's busy for the next 20 minutes, that's 20 minutes that we would have waited wondering what was going on. Instead he/she helped his/her patient and didn't break stride with that patient, we're not the only ones here, but he/she said, "tell them that she's stable, that nothing's changed, that she's okay, but I'm busy with another patient." And I prefer that as opposed to speaking to him/her directly 25 minutes later. Every minute is uncomfortable. I would have been thinking, "Oh God, I wonder what she's doing." But when he/she said that, that was actually good. (Sister-in-law of P2, Single Interview, Day 2)	Trust, Cope



Strategy	Exemplar Quotes	Response
<b>Neg_Fail to Keep Apprised of Condition:</b> FM described the nurse as failing to keep the FM apprised of changes in the patient's condition	And the only thing about that was, I guess because we told them if it happened again, he wanted it to be put back in, but I would have appreciated the nurse calling to let me know that he had done that. But when I got here, that's when I found out. Because we had let all of them know that they call us if they need to...Yeah, he/she didn't call and let me know. But I would have, there wasn't anything I could do, but I still would have wanted to know... I guess he/she didn't want to disturb me or anything. But I have felt good that I haven't got any calls during the night. But now that I would have wanted to know. (Wife of P12, Third Interview, Day 17)	Did not report a negative outcome. Despite this, she reported trusting the nurse
<b>Neg_Give Inaccurate Information:</b> FM described the nurse providing them inaccurate information	Some will say, 'well nothing's changed since last night,' and then I will find out, yes he did have a seizure, ...well that to me is important to know in the overall scheme of things. So, I'm thinking that he didn't have a seizure for two days, when actually he did have one the day before, that sort of thing. (Domestic Partner of P8, Single Interview, Day 9)	Unprepared, Misinformed
<b>Neg_Guess at What Might Be Wrong:</b> The FM described the nurse guessing at what might be wrong	[Nurse 1] was just like, 'oh, I don't know, this is kind of what I think is going on.' Where [Nurse 2] was like, if he/she didn't know he/she wouldn't even tell you. He/she was like, 'yes and you might want to talk to the doctor about that.' It wasn't guessing. And I like that...[Nurse 1] said, 'well we hear some crackling, we don't really know what it is, but this is what it might be.' I didn't have the same confidence. I didn't feel good leaving. I didn't. You know, I didn't. (Wife of P11, First Interview, Day 4)	Lack Confidence

Strategy	Exemplar Quotes	Response
<b>Neg_Leave FM hanging:</b> FM described the nurse not coming to the phone when the FM calls or telling the FM they will get back to them and failing to do so.	I called at two o'clock this morning to see how he's doing. And whoever answered the phone said, "just a minute" and then he/she got back and said, "I know that it's in the middle of the night, but you're going to have to call back in an hour." And right away I'm thinking, is he/she working on him is there something, and I didn't know if something was wrong or anything like that. So I waited, and I called back and he/she said no change, and that was it, not much of a change so. For the hour or so just wondering what's going on. (Wife of P5, Second Interview, Day 6)	Difficulty Coping
<b>Neg_Unable to Answer Questions:</b> FM described the nurse being unable to answer their questions satisfactorily and not finding the answers to these questions.	So that was frightening, very frightening for me...And the nurse hadn't got report yet because he/she had just picked them up. So [the nurse] didn't have the answers to our questions and was a little bit short because he/she was overwhelmed. He/she was like, "I don't have the answers to your questions"... I've been there, so I was torn because I know what it's like, he/she knows if a number looks bad, knows what to do, knows how to address that. So regardless of what his story is, he/she is going to act properly in an acute setting. But in my mind I'm thinking God I'm wanting [the nurse] to know everything. I want everything to be exactly right. So, in my mind I'm thinking that, but on the other side I'm thinking he/she's going to handle it, he/she's going to get report, and we're going to move forward. So, I was a little bit torn. (Daughter of P3, Single Interview, Day 3)	Difficulty Coping

#### **4.4.6 Approach: Support Decision-Making**

Although many family members described wanting just factual information from nurses, others appreciated when nurses supported their decision-making by interpreting factual information and discussing the nature of the decisions. Family members also described being supported by nurses remaining unbiased. When family members perceived that a nurse was biased or unaccepting of their decisions, they expressed feeling judged and lacking trust in that nurse. (See Table 13).

##### **4.4.6.1 Interpretation of findings**

Family members described nurses directly or indirectly interpreting the meaning of factual information for the likelihood of the patient's survival and quality of life. Most of these descriptions involved indirectly indicating the poor prognosis rather than directly speaking with the family member about the possibility that the patient might not survive. Family members differed in their preference for this type of information from the nurse. The need for information sometimes conflicted with the need to remain hopeful. Family members expressed a desire for nurses to remain optimistic and not express pessimism; family members also expressed that they did not want nurses to tell them that their loved one was not going to survive. Yet, family members also stated that they appreciated honesty and did not want anything "sugar-coated." Family members indicated that they appreciated when nurses hinted at the prognosis by reminding the

family member that the patient was still very ill, pointing out that the patient's condition had worsened or was unchanged from day to day, verbalizing uncertainty about the prognosis, and using body language and facial expressions to indicate a poor prognosis. The family members described nurses indicating a poor prognosis in ways that allowed them to be informed and prepared but also to remain hopeful. A granddaughter related how much she appreciated the honesty balanced with concern for her emotional well-being because it allowed to her to simultaneously have hope and prepare for her possible death, including having the opportunity for closure:

I know that kind of a few times they've said...they're never negative... like they've been positive, but then they'll kind of say 'but she's still...she's still got a long recovery, a long ways to go' or 'she's still really sick.' That kind of thing, so it's like they want to point out the positives and what has improved, but it's like they don't want us to get too....I think they wanted us to know what had improved, but they still wanted us to know the reality of the situation...Just I mean, I of course want to hear how she's improving, but I don't, like I said, I didn't want to ...I don't want to leave at night thinking 'she's definitely going to be here.' (Granddaughter of 14, Single interview, Day 6)

Although the family member participants rarely described nurses telling them directly that their loved one was dying, one family reported that a when nurse told her that her loved one was likely to die that night, it helped her to be prepared and have closure:

I was in there sometime there by myself, I said, 'Nathan, I want you to know how much I love you, and I want to tell you how much I want to appreciate you accepting me as your sister.' It could have been, well, she's not, she's not really ours, but that was never the case...[The nurse] told me it could be tonight or

early in the morning. And I appreciate that...I said, 'can you tell me,' and he/she said, 'tonight or in the morning.' ... I think it's important with anybody to have that [closure] don't you? I think that's why some people can't get over death, sudden death, family deaths if they have not had that. They've either not had the closure or they've got some guilt feelings. And I've got both. I mean, I think I did my closure thing when I told him thank you for accepting me. And I loved him. I think he could see it. And I think I can accept it. (Sister of 5, First interview, Day 5)

Very few family members described nurses engaging with them in frank discussions about the possibility of death and the meaning of information in the trajectory of the patient's illness. Although the participant above expressed that she wished that the nurses would be more engaged in discussions of death and dying with the patient's wife, whom she believed had false hope, most family members suggested that these discussions were the realm of physicians. Several family members reported that they appreciated when the nurse was optimistic. One participant indicated that she not want the nurse to tell her that the patient's prognosis was poor so that she could remain hopeful, saying:

Well it's a glimmer of hope, but they are not so, 'oh no he's not going to make it,' or 'I've never seen anybody come through this.' Just, if they've got that opinion, they are not saying it, so that I can hold on to that glimmer of hope." (Wife of P11, Second Interview, Day 8)

When family members were given only optimistic information or were given information that was indirect or vague, they were at risk for developing an unrealistic hope for recovery and being unprepared for the possibility of death. One such case

involved the daughter of a 59 year old woman with a very poor prognosis. The daughter described recent discussions with physician and nursing staff that focused on possible recovery and discharge home:

They are saying now she is progressing to recovery, so that makes everything a little bit easier...So, I'm not looking more towards having to do funeral arrangements and that kind of thing, or think the worst of the situation; I'm more looking towards just preparing her to come home and taking care of her.  
(Daughter of 15, Second interview, Day 10)

At this same point in time, the nursing and physician staff held little to no hope for the patient's survival. The day after this interview, I encountered this same daughter in the hallway in tears. She described having been told by the physician that her mother wasn't doing well. She expressed anger, confusion, and sadness and said she couldn't understand why they seemed to be giving up on her mother. What appeared to this family member as a rapid shift from hopeful and encouraging to hopelessness left her unprepared to make decisions about the care her mother would receive and risked eroding her confidence and trust in the staff.

#### **4.4.6.1 Remain unbiased**

Family members described that nurses supported their decision-making by remaining unbiased in the face of decision-making, including leaving the decision to the family member, avoiding personal opinions, and accepting the decisions that the family member made. One family member expressed that, although she did not perceive that

the nurses' input played into her decisions, she appreciated the nurses' support for her decisions:

And so it didn't play into it, but it just helped me; it felt good to know that they supported me, meaning 'if that's what you want, we'll keep you comfortable, we'll keep pain-free if that's what you want.' It was never 'I'd do the same thing.' None of that, it was always, 'if this is what you want we will.' (Sister of P9, Second Interview, Day 5)

This same family member voiced her appreciation for the nurses not rendering a personal opinion but leaving the decision up to the family member.

In the one case where a family member perceived that a nurse was biased, the family member expressed feeling judged and lacking trust and confidence in the nurse.

#### **4.4.6.2 Discuss nature of decisions**

Family members described nurses engaging in discussions about EOL decisions only after the physician had initiated such discussions with the family. The strategies that nurses used included discussing code status, discussing available options for care, discussing trade-offs and consequences for the various options, discussing the goals and values of the patient, expressing a desire not to inflict pain on the patient, and describing what to expect if the focus of care shifted from curative to palliative. Family members also described behaviors that helped them to reframe hope.

The sister of a patient described the nurse providing her with information about the options available and the consequences of those options:

The way they explained it is that what would happen is if we take him off antibiotics, which he's on now, if we take him off platelets, if we take him off the blood pressure medicine and all that, we can keep him comfortable; he just won't have any help in continuing life. And they said, 'is this what you want because if this is what you want, and you tell the doctor then you know...' (Sister of P9, Second Interview, Day 5)

The wife of a patient described how helpful it was to her when a nurse explained what would happen if they decided to withdraw life support:

When that time should come, what is the protocol for the patients and the family, are we able to...stay in that room, is he taken to a private area.' And they just explain, 'no, you will probably stay in that room.'... and that they would pull the curtain and just allow us to be there with him. I mean it's not something I want to have to have that conversation about. But, it's a conversation I needed to know because the kids had asked me. Mom, 'where do we go do this?' So, I needed to know. They would just kind of back off of care. Yeah, because it gives you time to think about what to expect if it gets to this point down the road, and you're not just suddenly there. [It was helpful because] I don't want to just end up there and go, 'okay what now?' I want to have a little bit, a little bit, I know everything can be different, but a little bit of what might happen, and what to expect. And our main goal is keeping him comfortable, not in distress, those kind of things. And that we are able to be there with him. (Wife of P11, First Interview, Day 4)

This discussion about what to expect helped her to prepare herself and her family for what might happen.

Although no family member described a nurse having a frank discussion about goals of care and values, some family members described nurses using indirect strategies to tangentially explore the values and goals of patient care. One nurse hinted that a patient might have been expressing a desire to not continue life support by pulling



out the endotracheal tube. Another nurse agreed with the family member that a will to live is important in a patient's ability to recover. A third nurse discussed the patient's quality of life:

I think I had asked the question, 'how long do you think the doctors would plan to keep him on the ventilator?' And [the nurse] said, 'oh you can keep somebody on a ventilator for years.' I was like, 'no, I mean like here before they are ready to do something different,' and we had a conversation about that, and... [the nurse] said oh yeah we can keep him on the ventilator for years, but then you have to look at the quality of life that they are going to have. What are they going to have, you know? (Wife of P11, Third Interview, Day 12)

Although several family members were able to reframe their hope from hope of cure to hope for a peaceful death, only one family member describe the nurse being actively involved in this process. The nurse expressed to this family member that she did not want to inflict pain on the patient with continuing aggressive care. She also reassured the family member that she would do everything she could to provide comfort for the patient:

[The nurse] said, 'As long as I'm here taking care of her, I'm going to do everything that I can to make her as comfortable as possible'...It helped a lot; it helped a lot because God is a God of miracles, so I pray for one, but at the same time if it's His will to have my mom with Him, I guess I came to a point where I've got to accept it... I felt very very...comfortable; I even slept better at night knowing that [that nurse] was here with mom and stuff, so I felt better. (Daughter of P15, Third Interview, Day 14)

This nurse's ability to frankly explain what continued aggressive treatment would entail

and to assure that the patient would be comfortable helped this family member to reframe her hope, to cope with situation, and to accept that her mother might die.

Some family members indicated that the nurses did not discuss any decisions with them and avoided bringing up the topic of end-of-life. One family member in particular expressed dismay that the nurses were not talking to her sister-in-law, who was the health care power of attorney, about EOL decisions:

The main thing they [nurses] are doing is just sitting there...on the-[computer]. I'm not criticizing them, but they will...say, "everything is about the same." ...I don't know who would it would be, Lord I don't know. But it's time, that somebody let Darlene, and I'm not being ugly, you know that I love him very much. But it's time that somebody...told her it's time to start dwindling him off. I think. Am I wrong to think that? Do you get how long this has been? (Sister of P5, Second Interview, Day13)

Although this participant was not the decision-maker, she indicated that what she perceived as avoidance of EOL discussions was delaying decision-making.

Although the family members rarely described nurses actively involved in the decision-making process, they described nurses supporting their decision-making by indirectly interpreting the information about the patient's condition, remaining unbiased, and discussing the nature of decisions. Family members reported in some cases that the strategies used by nurses helped them to accept that their loved one was dying, to have closure, to cope, and to have hope. Only one family member described her perception that the nurses were avoiding EOL discussions and her belief that this

was delaying decision-making. Another family member described hearing optimistic information from the nurses and having hope that her mother would survive, only to hear the following day that her mother's prognosis grim. Her response was dismay, distrust, and difficulty coping.

**Table 13: Approach: Support Decision-Making**

Strategy	Exemplar Quotes	Response
<b>Interpretation of Findings:</b> FM described the nurse providing information that included some level of indication of what that information means for the patient's prognosis for survival and/or quality of life.		
<b>Avoid False Hope:</b> FM described the nurse providing realistic information and not giving false hope.	So I think they wanted us to know what had improved, but they still wanted us to know the reality of the situation. Like they didn't want to give us false impressions that she's doing better...I don't think that's a bad thing; I think that's actually good. I wouldn't want them to lead us to believe that everything's going to be okay... if it wasn't so. Of course I want to hear how she's improving, but I don't want to ...I don't want to leave at night thinking 'she's definitely going to be here.' (Granddaughter of P14, Single Interview, Day 6)	Prepared, Trust
<b>Comparisons:</b> FM described the nurse comparing the patient's condition from one day to the next.	I ask [the nurse], 'Do you think he's better?' They are like, 'well, you know, this number is a little better than it was yesterday.' Or you know, 'this one is a little worse.' You know, I've asked, 'is his liver better?' 'No, it's a little worse today.'... It just helps me internalize things and be able to think about, okay, where we are at, what we might be facing. (Wife of P11, Second Interview, Day 8)	Prepared, Accept, Make Decisions

Strategy	Exemplar Quotes	Response
<b>Describe the Severity of the Illness:</b> FM described the nurse has emphasizing how gravely ill the patient is.	I think [the nurse] was trying to...he/she knew the closeness that we had, and I think he/she was trying to let me know that he is a sick man. And I needed to know it. And it's better to know something like that than to have it slap you in the face and be shocked but. He/she was very open about the fact that he was very sick. But he/she just stressed that, about how bad he was, he/she just said he is very sick and that he was the sickest person they had on the floor. That's not ugly, that's not him/her saying something he/she shouldn't say. I would not have wanted to walk in and [patient] be gone. I had rather you tell me, 'you know your brother is very sick.' And I can go to bed at tonight and lay my head on the pillow and know that I have done, I have been there with, I don't have any grudges to... In my Christian faith and if you've got something you hold it against somebody, you better get it straight. You don't need to have them anyhow, but you need to get things....I was in there sometime there by myself, and I said, '[patient] I want you to know how much I love you, and I want to tell you how much I want to appreciate you accepting me as your sister.' It could have been, well, she's not, she's not really ours, but that was never the case...and I think closure, that's what I was saying instead of being slapped in the face. (Sister of P5, First Interview, Day 5)	Closure, Prepared, Accept
<b>Describe the Severity of the Illness</b>	[The nurse] used the words 'his lungs looked bad,' but nobody had really used those before. So I kind of appreciated the honesty...I think he/she conveyed how serious it is...but I think I'm most hopeful that my husband just finds some peace, either peace by being healthy or peace by just you know being at peace<<cries>>. Because he just, like I said, he's taken so much for so long and...(Wife of P17, Second Interview, Day 9)	Hope

Strategy	Exemplar Quotes	Response
<b>Describe the Severity of the Illness</b>	They constantly let me know that she is very sick...just be aware that she is still sick, and she has to, it's all about her, her body and how strong she is right now to receive the treatment and the medicines to recover I mean, they are just wanting me to know that this disease that she has, it's a disease that kind of hits hard. Like, when it hits, it hits hard. And it puts you in a condition like my mom is in, to where she kind of needs support from both sides. I mean, I think what they want me to just keep in mind, that if for some reason the medicines and things do not work, or if their treatments are not, or if her body is not strong enough to accept the treatments, just to keep me informed that it's the disease, and it's not my fault, and it's not her fault, but it's just what she's up against and what she has to fight against, her body and everything, so. And they're just letting me know that they are doing everything in their power to make sure, to get her strong enough to where she can endure all of this. (Daughter of P15, Second Interview, Day 10)	Cope, Prepared
<b>Hint at Prognosis:</b> The FM described the nurse hinting that the prognosis is poor without coming out and directly saying that the prognosis is poor.	I said, 'things don't look good,' and [the nurse] said, 'no.' And just kind of gave me that look, and just did one of these and like, no, it's not. [patted my back and looked at me to demonstrate what the nurse had done to her]...It helps me help my kids to say when they came back...'things are not good today guys.' And then it didn't take me long to figure it out that it really wasn't good. (Wife of P11, Second Interview, Day 8)	Accept, Prepared

Strategy	Exemplar Quotes	Response
<b>Hint at Prognosis:</b>	I know that kind of a few times they've said...they're never negative... like they've been positive, but then they'll kind of say 'but she's still...she's still got a long recovery, a long ways to go' or 'she's still really sick.' That kind of thing, so it's like they want to point out the positives and what has improved, but it's like they don't want us to get too.... or up until this point because there's been a few days earlier in the week that we didn't think, and I don't think anybody thought she would make it. So I think they wanted us to know what had improved, but they still wanted us to know the reality of the situation...Just I mean, I of course want to hear how she's improving, but I don't, like I said, I didn't want to ...I don't want to leave at night thinking 'she's definitely going to be here.' (Granddaughter of P14, Single Interview, Day 6)	Prepared, Closure, Trust, Hope
<b>Honesty:</b> FM described the nurse being honest and forthcoming with information.	So I want to hear what's-tell me, just tell me the truth. Don't sugar-coat it... they were very open and explained pretty much anything we want, any question we had they explained it...well I mean at that point, you consider both um...how he's doing and again what his wishes are. And with our father, he's that ornery old type that he does not want to be strapped up to the machines. So it's one where the knowledge of what they're telling you versus our knowledge of knowing him and how he is; it's just like you kind of put it all together and well and, like the three of us were here the two of us plus our mom were here today. And it was kind of a consensus so um...okay, we have all the information the doctors and nurses can give us... He wants this tube out, we're going to adhere to his wishes, and we're going to see what happens. And we were one hundred percent prepared if he didn't make it, we were a hundred percent prepared for if he did. So we knew all the possibilities. I mean but that's good, that's about as much as you could ask for. (Son1 of P6, Single Interview, Day 3)	Make Decisions

Strategy	Exemplar Quotes	Response
<p><b>Tell FM Patient is Likely to Die:</b> The FM described the nurse has discussing with them a poor prognosis, including telling the FM that the condition is terminal or incurable or that the patient is not likely to make it through the night. Not the same as saying the patient might not survive but there is hope.</p> <p><b>Verbalize Uncertainty:</b> FM describes the nurse indicating that there is uncertainty about whether or not the treatment will be effective.</p>	<p>[The nurse] told me it could be tonight or early in the morning. And I appreciate that. We were just talking about his condition, how grave it is, and I said, 'well I know that the man tried to tell us of a time frame today, and [patient's wife] wouldn't hear it.' I said, can you tell me,' and he/she said, 'tonight or in the morning' ... I think it's important with anybody to have that [closure] don't you? I think that's why some people can't get over death, sudden death, family deaths if they have not had that. They've either not had the closure or they've got some guilt feelings. And I've got both. I mean, I think I did my closure thing when I told him thank you for accepting me. And I loved him. I think he could see it. And I think I can accept it." (Sister of P5, First Interview, Day 5)</p> <p>It is [very reassuring]...to know beforehand what the possibilities are...because when they do happen, then you're not in shock. You can kind of prepare for things. Well I mean they've been candid enough to tell me that the possibility is always there that she could not make it through this. And um...the possibility is there that she doesn't have enough intestine left that she will be able to support nutrients from eating. It could possibly have to be fed through veins. Um things like that they've been up front with me. And uh, but at the same time, they give me hope in saying she may have enough to do that; we just don't know yet. And that she's got a hundred centimeters of small intestine left, and a lot of people can do that with eighty. So like I said, I just couldn't ask for it to have been any better as far as communication and the caring for my mom and me. (Son of P14, Single Interview, Day 5)</p>	<p>Closure, Accept, Prepared</p> <p>Prepared, Trust</p>



Strategy	Exemplar Quotes	Response
<b>Neg_Avoid EOL Discussions:</b> The FM described the nurse (or other HCP) not engaging in discussions about poor prognosis, goals, or EOL decisions.	<p>The main thing they're [nurses] doing is just sitting there...on the-[making typing movements with her hands] I'm not criticizing them but they will...say you know, "everything is about the same." ...I don't know who would it would be, Lord I don't know. But it's time, that somebody let [wife]-and I'm not being ugly you know that I love him very much. But it's time that somebody...told her it's time to start dwindling him off. I think. Am I wrong to think that? Do you get how long this has been? (Sister of P5, Second Interview, Day 13)</p>	<p>Delay Decision-making</p>
<b>Neg_Avoid EOL Discussions</b>	<p>I'm just really wrestling with him being in the agony or struggling because he didn't seem very comfortable today, even with the-because they didn't want to give him the amount of sedation they normally would because he's had such a hard time coming to, as it is. And yesterday we did talk about the possibility that he may have had a stroke through this time or suffered some kind of...I don't want to say brain damage but some sort of mental problem. And it's really difficult for me just because I know how he feels about that, and he just doesn't want to live that way. He was like, 'I never ever, don't ever let me be like that.' And I don't know, I guess I'm just really worried. His dad aspirated and died the same day. I remember that because my husband was really sick then too, and they called me and said 'he's aspirated; we're going to treat him,' and then he was dead at five o'clock. And so I guess I'm just sitting here wondering, I was watching my husband's BP, and it's just sliding down and stuff, and I just hope that there, if that's where we're headed, they'll be honest with my son. (Wife of P17, Second Interview, Day 9)</p>	<p>Difficulty Coping, Lack of Hope</p>

Strategy	Exemplar Quotes	Response
<b>Neg_Give False Hope:</b> FM described the nurse giving them hope for the patient's survival when the HCPs have indicated to other HCPs and to the PI that they have little or no hope for the patient	Well, they have been very good with letting me know, like how her blood pressure and everything is stabilized, and they tell me about the dosage of the medications, they let me know what meds they are giving her, and they let me know what they've done throughout the day, that they've bathed her, that they are moving her every two hours to prevent any more sores from happening. They have been very informational as far as letting me know how well they are caring for her and how she is taking the meds... It's very helpful, it lets me know that she is still holding on, and she is still...it helps me to feel like she can recover from this. So ... It gives me a lot of hope. (Daughter of P15, Second Interview, Day 10)	Hope, Cope, Unprepared, Difficulty Coping
<b>Neg_Give False Hope</b>	Well, I mean, they haven't said anything as far as her not making it. That's a big thing with me. No one has said, 'anything could happen at this point;' no one is saying that. Like, 'anything could happen, like it's more of a 50/50, like before.' They are saying now she is progressing to recovery, so that makes me, that makes everything a little bit easier...So, I'm not looking more towards having to do funeral arrangements and that kind of thing, or think the worst of the situation; I'm more looking towards just preparing her to come home and taking care of her. (Daughter of P15, Second Interview, Day 10)	Hope, Cope, Unprepared, Difficulty Coping
<b>Discuss Nature of Decisions:</b> FM described the nurse discussing the decisions, consequences of decisions, and meaning of decisions.		

Strategy	Exemplar Quotes	Response
<b>Describe What to Expect:</b> The FM described the nurse has explaining what to expect. This included what the FM might see when they enter the room, what to expect in a family meeting, what to expect if life support is withdrawn or withheld.	When that time should come, if it comes, what is the protocol for that, what is the protocol for the patients and the family, are we able to, do we stay in that room, are we, is he taken to a private area.' And you know, they just explain, 'no, you will probably stay in that room'...Pull the curtain, he would not be receiving as much care, like checking his blood pressure every few minutes, and that they would pull the curtain and just allow us to be there with him. I mean it was okay, it's not something I want to have to have that conversation about. But, it's a conversation I needed to know because the kids had asked me. Mom, 'where do we go do this?' So, I needed to know. They would just kind of back off of care. Yeah, because it gives you time to think about what to expect if it gets to this point down the road, and you're not just suddenly there. [It was helpful because] I don't want to just end up there and go, 'okay what now?' I want to have a little bit, a little bit, I know everything can be different, but a little bit of what might happen, and what to expect. And our main goal is keeping him comfortable, not in distress, those kind of things. And that we are able to be there with him. (Wife of P11, First Interview, Day 4)	Prepared, Trust
<b>Describe What to Expect</b>	[The nurse] said, 'well when you see him it's going to look really, really bad, but know that most facial injuries do look,' and he/she explained and that helped me because I thought if he/she hadn't said that and I walked in I would have thought, he's getting ready to die like right now. Do you know? So he/she prepared me just a little bit of his facial wounds. (wife of P10, Single Interview, Day 2)	Prepared, Cope

Strategy	Exemplar Quotes	Response
<b>Discuss Code Status:</b> FM described the nurse discussing the code status	Interviewer: I remember [nurse name] mentioning to me yesterday that she was afraid that he might code. Did she tell you that? Wife: Yeah wouldn't make it-I think he/she mentioned because of his liver test, yeah. Interviewer: What was that like to hear that? Wife: Not good, but I appreciate the honesty, and uh he/she wasn't saying that because he/she was pushing for anything, like the doctors do they just want to get someone out and get the next person in or whatever...Because uh...just it's a possibility. And uh, he/she's taken care of a lot of patients in the seventeen years. (Wife of P5, Third Interview, Day 11)	Confident, Trust
<b>Discuss Options:</b> FM described the nurse discussing with them different treatment options available.	Well yes they talked to me about the options about taking everything off at once or taking things off gradually...they made sure I understood, this is what your options are, 'if this is what you want, this is what it's going to be. If that's what you want, it's your decision.' (Sister of P9, Second Interview, Day 5)	Make Decisions, Trust, Comfortable with Decisions
<b>Discuss Trade-Offs:</b> FM described the nurse discussing with them the potential outcomes of different treatment options.	The way they explained it is that what would happen is if we take him off antibiotics, which he's on now, if we take him off platelets, if we take him off the blood pressure medicine and all that, we can keep him comfortable, he just won't have any help in continuing life. And they said, 'is this what you want because if this is what you want, and you tell the doctor then you know...' (Sister of P9, Second Interview, Day 5)	Make Decisions, Trust, Comfortable with Decisions
<b>Discuss Trade-Offs</b>	They wanted us to be assured that, especially because he's so agitated all the time, that they're doing everything that they can to make him comfortable. [They explained] that even though one medicine may be helping him with one thing, the other thing counteract that, but you've got to work with it, you've got to look at the entire picture and understand what's going on, and they have, they've been good explaining to us what they are doing. (Wife of P12, Second Interview, Day 8)	Confident

Strategy	Exemplar Quotes	Response
<b>Discuss Trade-Offs</b>	We ask a lot of questions of Nurse L., and has he/she ever seen anyone, what happened, if they put the trache in, what does that mean? Will he be able to talk? And he/she explained you could put fingers over it, and they could say some words; he/she explained all that. The feeding tube, I said have you ever worked with patients that have had this done. And just hearing about what he/she had to say it was reaffirming to us...Just in his/her experience, and it seemed like he/she said something, I can't remember, seemed like it was his/her father or something, or maybe it was some patient. I remember him/her saying something he/she had worked with patients that had had this done. And he/she worked with him enough that he/she knew his, or confirmed with us, his degree of agitation when he...(Wife of P13, Second Interview, Day 14)	Comfortable with Decisions
<b>Explore Values:</b> FM described the nurse asking about their understanding is of the patient's values, what is important to the patient and the FM, and exploring FM's understanding of the goals of care.	And [the nurse] was confirming of, again it was more my words than his/her words, he/she was confirming that, 'yes there is the will to live. If you don't want to live, I don't care.' It doesn't matter. So I am hopeful. I'm hopeful... but if my father wants to go, he's going to go, no matter what we do so. (Daughter1 of P13, First Interview, Day 3)	Prepared, Trust
<b>Explore Values</b>	Yeah, well I forget the words exactly, but when he [patient] pulled the tubes out, I mean they're all- it's like yeah, it's clear what he wants. And you know it's almost funny because you know I can see him doing that. Uh...yeah 'cause I mean it, if you ever needed that last little...you know, yes you're doing the right thing I mean yeah that was...(Son1 of P6, Single Interview, Day 3)	Comfortable with Decisions

Strategy	Exemplar Quotes	Response
<b>Reframe Hope:</b> The FM described the nurse helping them to have hope for something other than what they originally were hoping for.	Yeah the nurse let me know how her condition was and just said 'you don't have to let go of her; you just let leave it up, you let nature take its course and leave it up to God,' and he/she said, 'as long as I'm here taking care of her, I'm going to do everything that I can to make her as comfortable as possible...It helped a lot; it helped a lot because God is a God of miracles, so I pray for one, but at the same time if it's His will to have my mom with Him, I guess I came to a point where I've got to accept it...Yeah [the nurse] did. He/she really did I felt very very...comfortable; I even slept better at night knowing that he/she was here with mom and stuff, so I felt better. (Daughter of P15, Third Interview, Day 14)	Hope, Confident, Accept, Cope
<b>Reframe Hope</b>	Yeah I mean I am, I'm hopeful, I'm hoping, but I know that she can't be on these machines. I know she can't just keep being on these machines. But I mean I don't want her to suffer; I really don't want that. I'm just hoping that there's no pain... They're [nurses] saying they're going to keep treating her and...making her as comfortable as possible and making sure she's not-that she won't be in any pain, and if she's in pain, they're going to make sure that she, that pain is removed. They let me know, they're going to make her as comfortable as possible so. (Daughter of P15, Third Interview, Day 14)	Hope, Confident, Cope

Strategy	Exemplar Quotes	Response
<b>Say You Don't Want to Inflict Pain on the Patient:</b> FM described the nurse indicating a desire not to cause pain for the patient.	<p>P43:26. 1501. Yeah [the nurse] was just saying how he/she didn't want to inflict any more pain on her; they were saying about changing out those lines and stuff and [the nurses] was like that's going to hurt-it's painful because it's in her neck. And that dialysis thing is like, it's really, they just came to me and was like, 'it's really going to hurt her,' and it could even be a possibility to where she could...it could make her blood pressure drop or it could hurt her so bad to where her heart could even stop, so I don't want that, so I was appreciative of them telling me that ... It was hard to hear them say that, but them being honest it helped, it helped...Yeah, it did [help with decision] because I was thinking 'please just do whatever you've got to do' I was thinking 'I don't care what you do, do what you've got to do' but when they came in and was like Sharlene, 'you just, we don't want to keep inflicting her pain on her; she done been poked so many times, and she gots these lines and stuff in her; we don't want to keep doing that and seeing her hurt and suffer.' And you know they the ones that have to do it, so I understood what they were saying, and it just showed that they cared a little more than a nurse would so. (Daughter of P15, Third Interview, Day 14)</p>	<p>Make Decisions, Comfortable with Decisions, Cope, Trust</p>
<b>Remain Unbiased:</b> FM described the nurse discussing decisions without bias		
<b>Accept Decisions:</b> FM described the nurse verbalizing or demonstrating acceptance of their decisions. Includes avoiding the appearance of pushing FM to make a decision.	<p>And so it didn't play into it, but it just helped me um, it felt good to know that they supported me, meaning 'if that's what you want, we'll keep you comfortable, we'll keep pain-free if that's what you want.' It was never 'I'd do the same thing.' None of that, it was always, 'if this is what you want we will.' (Sister of P9, Second Interview, Day 5)</p>	<p>Comfortable with Decisions, Trust</p>

Strategy	Exemplar Quotes	Response
<b>Accept Decisions</b>	That, it was comforting to know that we had made that decision and that, based on Roger's personality and his degree of agitation, that he would not have wanted that in his throat. Yeah, yeah. [The nurse] didn't say yay or nay; he/she just said... we explained...his degree of agitation when he gets tired of something. And [the nurse] laughed and said, 'I have gathered that' because he/she had seen a little bit of it. And it was just, I guess reconfirming that, what he/she saw in Roger and what we explained to him/her that he/she thought that we had made a good decision. But he/she never said yay or nay. But he/she just told us his/her experiences. (Wife of P13, Second Interview, Day 14)	Cope, Comfortable with Decisions, Trust
<b>Avoid Unsolicited Recommendations or Advice:</b> FM described the nurse avoiding giving recommendations.	Oh very supportive, definitely we never-you always felt like you were doing the right thing. I guess there was no emotion or reaction that, where you could read-it's like 'oh I wouldn't do that to my family.' You know you never had any adverse reaction; it was you know just kind of a very- Implicit, just more implied agreement that this was the right action. (Son1 of P6, Single Interview, Day 3)	Comfortable with Decisions, Trust
<b>Avoid Unsolicited Recommendations or Advice</b>	I've not seen where they've given their opinions. I've only seen, so far knock on wood, this far, that they honestly give you the medical side of things. It's never their opinion, their feeling. It's never how they think, it's never what they would do, it's never any of that, and I like that...They've not ever said 'well if it was my family member' or 'I can tell you right now it doesn't seem like he's going to make it,' they never do that. They are very careful in how they talk to you. Or telling you that they don't think he's going to make it or they think-the nurses haven't done that. (Sister of P9, First Interview, Day 3)	Confident, Trust
<b>Leave Decision to FM:</b> FM described the nurse leaving the decision up to the FM and not pushing for any particular decision.	And I have been told more than once, 'it's your decision,' which I knew-they wanted to make sure you knew it's your decision...I've had to ask some things, 'like what are you putting in his tube, is it saline or is it morphine?' and they were like, 'I'm giving him more morphine because he looks like he's in a little bit of pain.' And they said, 'we can change that if you want, but it's totally up to you if you agree to change it.' (Sister of P9, Second Interview, Day 5)	Trust, Comfortable with Decisions, Make Decisions



Strategy	Exemplar Quotes	Response
<b>Neg_Lack of Support of Decisions:</b> FM perceives that the nurse is not supportive of the FM's decision	Just [the nurse] talking about the type, the diagnosis and well the white count is up, and they're not going to be able to do a transplant, and he's going to have to have three negative blood cultures before they would even consider, and I said "well I know, I'm aware that they have to get the infection under control first you know, before they do anything, and I want him, everything done for him to get to that point, to get everything under control and to get him back to where he can possibly have a transplant." And it's like they just want to give up, that's it you know...just go ahead doing something and not even looking and just doing something and couldn't even look you in the face it seems and coming at you, know what I mean...I was wondering if he was going to get good care when I wasn't there. (Wife of P5, First Interview, Day 5)	Lack of Trust and Confidence,
<b>Neg_Render a personal opinion:</b> FM perceives that the nurse has rendered a personal opinion	Um I guess maybe an opinion about..."well, if it were my family member"..."my mother has power of attorney for me and she knows exactly what I want" well, I also discussed this with my husband when we got this, when we did this... [I thought] Um that's fine for you but, you're not me and, everyone is different? And I don't really care what you want to do with your life and your family and I have the right to do... everyone's different. It's like questioning you, "does he really you know, is this really what he wants?" Like that sort of thing. (Wife of P5, First Interview, Day 5)	Lack of Trust and Confidence, Feel Judged.

## **4.5 Trajectory Analysis**

Trajectory analysis was used to determine if the family members' perceptions of nursing strategies changed over the period of time the patient was in the ICU. I had sufficient data to complete trajectory analysis on five of the patients, P5, P11, P12, P13, and P15. For each case, I entered the frequency of the use of strategies from each approach; the condition of the patient; any contextual events that occurred on that day; and the numerical rating of hope from the viewpoint of the family member, the nurse, and the physician. Analysis of the data from these five cases revealed a variation in the number and types of strategies used by nurses over the period of the ICU stay. The findings from the analysis of the trajectories of each case will be presented beginning with a description of the patient's illness trajectory followed by a description of the family members' perceptions of nursing strategies and their responses to those strategies. **Tables 14-18** provide descriptions of the contextual data, and **Figures 3-7** provide visual analyses of the trajectories.

### **4.5.1 Trajectory P5**

#### **4.5.1.1 P5 Description of patient illness trajectory**

The patient was a 65 year old Caucasian male with hepatic failure who was being evaluated as an outpatient for a liver transplant when he became acutely ill and septic. He was initially seen in another hospital then transferred to Duke University Hospital.

When I enrolled him he had multi system organ failure, with liver, kidney, respiratory, and cardiac failure and was on the ventilator, continuous dialysis, and two vasopressors. He had been intubated for three days prior to being enrolled in the study. The physician (attending or fellow) and bedside nurse rated their hope for his recovery as very poor. A family meeting had occurred the day before, and the wife indicated that she wanted to continue aggressive care. On the sixth ICU day a family meeting was held with the health care team including a palliative care attending, a gastroenterology fellow, an intensive care attending, a medical student, a social worker, and the nurse who was caring for the patient that day. The attending physician recommended that the code status be changed from full code to DNR. The wife requested that the patient remain a full code. On day seven the patient's condition remained poor; he had worsening mental status and was diagnosed with disseminating intravascular coagulation (DIC). On day nine, his mental status had worsened. The nurse told me that she hoped to talk to the wife about a DNR order over the weekend. On day 10, a nurse who had been caring for the patient on a consistent basis told the wife that she was afraid that the patient would "code" and that she did not want to do that to him. On day 11, after talking to her niece, who was an oncology nurse, the wife requested that the code status be changed from full code to DNR. On day 15 the patient was on maximum doses of two vasopressors. On day 17 the patient was on maximum doses of three vasopressors. He died that

afternoon on the ventilator and continuous dialysis. Table 14 summarizes the illness trajectory.

**Table 14: P5 Illness Trajectory**

	ICU Day 5	ICU Day 6	ICU Day 7	ICU Day 9	ICU Day 10	ICU Day 11	ICU Day 13	ICU Day 15	ICU Day 17
Condition	Multi system organ failure	Vent Lower 2 Pressors	Altered mental status	Vent 2 Pressors More lethargic	Vent 2 Pressors Worse	Vent 2 Pressors No Change	Vent 2 Pressors No Change	Vent Max dose 2 Pressors	Vent Max dose 3 Pressors
Contextual Events		Family Meeting MD recommend DNR	Diagnosed with DIC	RN stated she hoped to get a DNR order	RN told wife afraid he would code and did not want to do that to him.	Wife requested DNR		Family Meeting	Patient Died
Interview	Wife, Sister	Wife				Wife	Sister		
Wife Hope	4.3	4				4.3			
Sister Hope	1						1		
RN Hope	1	1	1	1	1	1	1	1	1
MD Hope	1	1	1	1	1	1	1	1	1

Note: Pressors = Vasopressive Medication  
Vent = Mechanical Ventilator

#### **4.5.1.2 P5 First Interview: Wife and sister, day five of ICU stay**

The wife and the sister were each interviewed separately on the first day of enrollment (day 5 of the ICU stay). The wife indicated that the nursing staff had demonstrated concern for her psychosocial and physical needs by bending the rules and by offering blankets and pillows when she stayed overnight. She expressed that this concern for her made her trust the staff and feel reassured that her loved one was receiving personalized care. The sister described a nurse providing encouragement, saying, “he has a good blood pressure, this is very encouraging” and expressed appreciation for being given a little hope.

In the category of building rapport, the wife described the nurses as approachable personable, and encouraging her to ask questions:

Yeah they made you feel very comfortable that you were not being a pain if you asked a question or anything, and they didn’t act if they were in a hurry. They were there to answer a question; they were not doing things around you.

Both the wife and sister indicated that the nurses’ approachability made them more trusting and more comfortable asking questions. The wife described two nurses who avoided engaging with her. “Just go ahead doing something...and couldn’t even look you in the face...They don’t say anything at all until you ask them something, and then they’ll answer that one question and that’s it.” She expressed that this behavior made her lack trust and confidence in this nurse and made her feel afraid to ask questions.

The wife described ways that the nurses demonstrated professionalism, including, demonstrating a calm demeanor, demonstrating competence and confidence, working collaboratively, and treating the family with respect. These strategies instilled confidence and trust.

The wife described how nurses provided her with information by explaining the patient's treatments and treatment plan. In addition she described the nurses giving her factual information about the vital signs and ventilator settings, which she interpreted as hopeful. She expressed that the explanations helped her to feel comfortable asking questions, to understand her husband's condition and treatments, and to trust the nurse.

The wife did not describe any positive experiences with the nurses supporting her decision-making in this interview. She described one nurse hinting at the prognosis by indicating that the patient was not going to be able to have a transplant in his current condition, she expressed anger and lack of trust, saying, "And it's like they just want to give up, that's it...I was wondering if he was going to get good care when I wasn't there." Later in the interview, she indicated that her lack of trust was based less on what was said than on how the information was delivered, indicating that the lack of concern and lack of attention to building rapport demonstrated by the nurse might have made it more difficult for her to receive the information.

The sister provided a different outlook; she described a nurse who had hinted at

the poor prognosis the night before by telling her how gravely ill the patient was. When she pressed this nurse further, the nurse told her that the patient was likely to die that night or the next day. She expressed appreciation for this news because it helped her to be prepared, to accept that her brother was dying, and to have closure with him.

The wife described two nurses who demonstrated lack of support and bias. One nurse looked up and shook her head during a family meeting, which the wife interpreted as lack of acceptance of her decisions. Another nurse shared a personal opinion saying, “well if it were my family member” or “do you really want this done?” The wife indicated that this caused her to feel judged and to lack trust and confidence in the nurse. The wife’s response to these behaviors might have contributed to her lack of trust and her insistence on continuing aggressive care to the end.

#### **4.5.1.3 P5 Second interview: Wife, day six of ICU stay**

The second interview occurred shortly after a family meeting was held in the conference room with the health care team including a palliative care attending, a gastroenterology fellow, an intensive care attending, a medical student, a social worker, and the nurse who was caring for the patient that day. During the second interview, the wife focused mostly on the nurse who was caring for her husband that day. She described this nurse providing personal care and comfort for him her husband and doing “extra things.” She also described this nurse as “nice” and “personable.” She



described the nurse's demeanor as calm and described him/her as well-informed. These strategies to demonstrate concern, build rapport, and demonstrate professionalism, helped her to have confidence in the nurse, to trust that the nurse cared about her, and to cope knowing that he was in good hands.

She described several strategies in the category of providing information. She expressed appreciation for the nurse's ability to answer any questions that she had. She described the nurse giving her information about laboratory values and about the procedures. She did not describe the nurse interpreting the factual information about the meaning of these findings in the trajectory of the illness. When asked about her hope, she expressed being very hopeful, despite what she was told in the family meeting by the physicians, and based this hope on her own interpretation of factual information and by what she saw:

Well since the labs, I'm kind of comfortable with that, and I think if all the infection can go down, that will be one more thing out of the way. And then with the dialysis, about the dialysis I asked her, because since this is a real slow process this kind 'oh that's going to take several days, it doesn't happen overnight' so by the time I guess that kicks in and works and the white count continues to come down, I'm moving this way [points to right side of the hope line, indicating she is more hopeful].

She described the difficulty coping that she experienced when she called in during the night to check on him and was told she would have to call back. She did not describe any strategies in the category of support for decision-making.

#### **4.5.1.4 P5 Third interview: Wife, day 11 of ICU stay**

The wife described the difference between nurses who were helpful and those who were not helpful. The nurse who was most helpful to her was the one who demonstrated concern for her and her husband by providing gentle personal care, talking to her husband while providing care, and demonstrating sensitivity about the delicate social situation in the family with estranged adult children. In addition, she described this nurse as having a positive outlook versus others whom she described as too negative. She described this nurse using several strategies to build rapport, including affirming her, encouraging her to ask questions, and allowing her to stay after visiting hours. While providing information, this nurse answered questions, provided explanations of the treatment, and provided factual information about the condition of the patient without interpretation of those facts. She described strategies that this nurse used in the category of support for decision-making including being accepting of her decisions and gently bringing up the topic of CPR by telling her that the patient might code that night and that he/she did not want to have to code him. She responded favorably to this conversation with the nurse about the code status and expressed that she felt this nurse talked to her about the code status because she cared, versus others whom she perceived were pushing her and just wanted to make room for another patient. She expressed that she trusted this nurse, was confident in the care and

reassured that her husband was receiving personalized care.

The wife described one or more nurses whom she perceived as being unhelpful. The behaviors she described included being rigid about visiting hours, not letting her sit close to her husband because of machinery being in the way, avoiding engaging with her, being curt with her, and being rough with her husband. She expressed dissatisfaction with the care and lack of trust and confidence in those nurses. Although she did not recall specific instances of one on one conversations about prognosis with nurses, she expressed dissatisfaction with the information given to her in family meetings, saying that she felt as though everyone was lining up to tell her that they were giving up.

#### **4.5.1.4 P5 Second interview: Sister, day 13 of ICU stay**

The sister's perception was very different than that of the wife. She described the nurses using strategies to demonstrate concern for her needs and build rapport:

[The nurse] said 'I think you deserve a hug.' Twice it happened. And I think things like that are just as important as that needle you're putting in...When they get to the...[showing] that they're people and that you're people, that you're not just something, you're not stuffed animal. That sounded ugly didn't it? You can get a stuffed teddy bear and set it anywhere, and he don't know what's going on, but you have feelings don't you? And...if it's somebody that you love. Instead of just walking on by me and going on by what he/she needed to do to the next patient, he/she said 'I think you deserve, need a hug.' [And that showed] compassion and that he/she cared.

These strategies helped her to have a personal connection with the nurses and to trust

that they cared about her.

The sister described nurses giving her information including answering her questions and explaining treatments. She also described a nurse hinting at the prognosis by telling her how very sick the patient was and one nurse who directly told her that the patient was dying. She expressed dismay that the nurses seemed to be avoiding giving the wife accurate information and decision support. She described that the information she heard the nurses give the wife seemed inconsistent with what she was hearing from the physician. She described one nurse using a personal story about a family member who survived a similar illness:

I've heard [the nurse say], 'Darlene, keep your faith up,' that he/she has a member of his/her family very sick, and they came back...If I had not heard that doctor that day, I would have thought, oh that's wonderful but I think he/she was giving her false hope.

She expressed concern that what she perceived as avoidance of frank discussions with the wife would delay decision-making and lead to increased suffering for her brother.

#### **4.5.1.5 P5 Informal interview wife: Day 17 of ICU stay**

As I entered the room on day 17, the wife pulled me aside and expressed anger that the nurse who was caring for her husband had said to her "he is losing his pressure because he is dying." She said, "too many people ask me, 'do you know how sick he is?' Of course I know how sick he is; they don't have to keep asking me." The patient died

while the wife was talking to me.

The trajectory analyses for this family unit, presented in Figures 3-4, demonstrate variation in the types and numbers of strategies over time. What stands out is how different the wife's and sister's trajectories appear. These two family members described very different experiences, yet presumably, they interacted with the same nurses. In the first interviews the wife and sister both described nurses building rapport, demonstrating concern, and providing factual information without interpretation or without any personal opinions. The wife did not note any positive decision-support strategies, and expressed lack of trust and difficulty coping when nurses hinted at the prognosis. Conversely, the sister described nurses hinting at the prognosis, describing the severity of the illness, and directly telling her that her brother was dying, indicating that these strategies helped her to cope, prepare, accept, and have closure. In the final interview the wife expressed lack of trust in nurses and physicians who reminded her of how sick her husband was. Yet, she expressed trust in the nurse who gently broached the topic of CPR, saying that he/she was afraid that he might "code" and did not want to have to do that to him. This was a nurse who had cared for her husband for several days and who was present at the family meeting. Although the wife stated to me that nothing any of the nurses had said played in to her decisions, the day after the nurse broached the subject of CPR, the wife requested a DNR order. In her final interview, the sister

described her perception that nurses were giving the wife false hope by being overly optimistic, giving false reassurance, giving information that was inconsistent that of the physicians, and avoiding EOL discussions. Figures 3 illustrates the trajectory of strategies for the wife and sister.

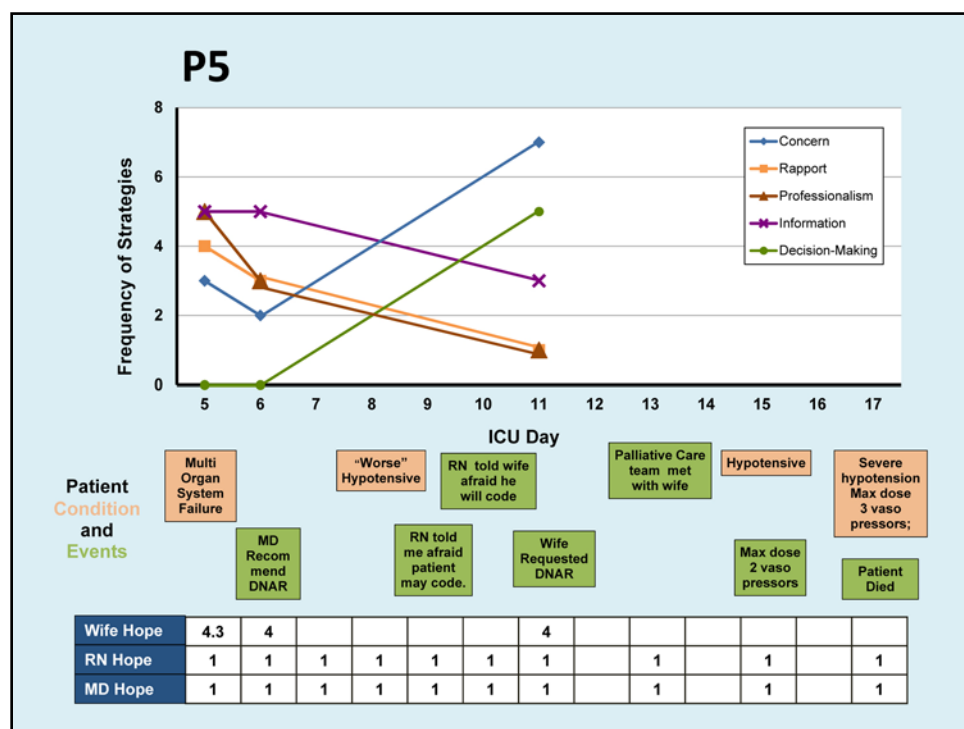


Figure 3: P5 Trajectory of Strategies

## 4.5.2 Trajectory P11

### 4.5.2.1 P11 Description of patient illness trajectory

The patient was a 65 year old Caucasian male with Hepatitis C and hepatorenal failure. He was admitted to the ICU with gastrointestinal bleeding four days prior to enrollment in the study. He had a banding procedure and a transjugular intrahepatic portosystemic shunt (TIPS) procedure to control the bleeding from esophageal varices. The bleeding had stopped, but his liver and renal function had worsened. He was sedated from high ammonia levels. He was on minimal ventilator settings and on vasopressors. The attending physician had told the wife that he had little hope for his ever being able to leave the hospital and recommended changing his status from “full code” to DNR. He further recommended that if the patient was able to breathe without the ventilator, to extubate him and not re-intubate if he developed respiratory failure (referred to as a “one way extubation”). On day five, the vasopressors were discontinued because they were no longer needed. On day eight, the patient’s condition worsened. His blood pressure dropped and he was started back on vasopressors. The physician discussed reversing the TIPS procedure because the liver and kidney function had worsened. The attending spoke to the wife about the level of aggressiveness of care. She indicated that she wanted to continue aggressive care as long as the patient was showing any improvement. On day 12 the attending told the wife and daughter that the patient was becoming “chronically critically ill.” He described his condition as like being on a “kiddie roller coaster” with one day a little improvement and one day a little

decline but the overall prognosis remains very poor. He again recommended “one way extubation.” The wife asked that the physician meet with the family the next day when her son would be there. The following day the family met with the attending physician and the patient was made a DNR and extubated. He died shortly thereafter.



**Table 15: P11 Illness Trajectory**

	ICU Day 4	ICU Day 5	ICU Day 6	ICU Day 8	ICU Day 10	ICU Day 11	ICU Day 12	ICU Day 13
Condition	Hepatorenal failure Vent 2 Pressors	Vent Off Pressors	Less responsive labs worse	Vent Pressors	No change	No change	No change	Vent Pressors Worsening renal function
Contextual Events	Attending told wife, not hopeful, patient might never go home. Discussed "one-way extubation"			BP dropped. Attending Discussed reversing TIPS procedure	Wife indicated that she wanted to continue aggressive care as long as there is some improvement		Attending met with family. Said patient becoming chronically critically ill. Recommended one way extubation	Attending met with family, suggested one way extubation. Sedation decreased and patient extubated
Interview	Wife			Wife			Wife	
Wife Hope	2			2			2	
Nurse Hope	2	2	1	1	1	1	1	1
MD hope	1	2	1	1	1	1	1	1

Note: Pressors = Vasopressive Medication

Vent = Mechanical Ventilator

#### **4.5.2.2 P11 First interview: Wife**

I interviewed the wife on day four of the patient's ICU stay. She described nurses using strategies to demonstrate concern for the patient's physical well-being by talking to him gently while providing personal care and by assuring his comfort. In addition, she described nurses demonstrating concern for the psychosocial well-being of the family by encouraging them to care for themselves and bending the visitation rules to allow more than two visitors at a time, which allowed the family members to support each other and instilled a sense of trust that the nurse cared about them and supported them as a family unit.

The wife described strategies that the nurse used in the category of building rapport, including listening to her and being patient with her as she asked questions. These strategies helped her to feel more comfortable asking questions.

The wife described strategies in the category of professionalism contrasting the strategies of a nurse who demonstrated professionalism with a nurse who demonstrated lack of professionalism. Her perceptions of the professional nurse were that he/she had a calm and confident demeanor. This nurse seemed to know what to do in a crisis and did not seem to need much help from other nurses but accepted help when needed. The wife described this nurse deferring to the physician if he/she did not know the answer to a question. She expressed that she felt confident in this nurse and was better able to cope

knowing that her husband was in competent hands. She perceived that the other nurse was less experienced. When she overheard this nurse in the hallway talking about grades on an exam, she interpreted that this nurse was a student and inexperienced. She said that she did not feel comfortable going home in the evening with her husband being cared for by the nurse whom she believed was inexperienced.

She perceived that these two nurses differed in provided information as well. She perceived that the “inexperienced” nurse was unable to answer her questions and seemed to be guessing at what was wrong, whereas the nurse whom she perceived as more experienced and confident was able to answer her questions readily and explain what was happening.

The wife described receiving factual information about the laboratory tests and ventilator settings that did not include any “personal opinion.” She said that she appreciated honesty and wanted to be told about findings, whether they were positive or negative, but she especially appreciated when the nurse gave her positive findings so that she could have a “glimmer of hope.” If she asked “is he better,” the nurse would give her facts, saying, “this number is better, this one is worse.” She expressed that this factual information allowed her to maintain hope but also to be prepared for what might happen. She related a distressing experience when she called in at night and was told to call back later. She expressed that this experience made it difficult to cope because she

was concerned that something was happening to her husband when in reality, the nurse was tied up with another patient and could not come to the phone.

The nurses provided support for her decision-making by providing comparisons from one day to the next, which allowed her to assess his worsening condition. One nurse also described what to expect if the family made the decision to withdraw life support, which helped her to prepare herself and her family for this possibility. She described the nurses hinting at the prognosis, saying, he is “walking a fine line.” She also described the nurse avoiding false hope by not telling her, “he will be okay” when evidence pointed to the opposite.

#### **4.5.2.3 P11Second interview: Wife**

The second interview was conducted on day eight of the ICU stay. As in the first interview, the wife described the nurse bending the rules and assuring patient comfort. However, she described one nurse who demonstrated lack of concern for her emotional well-being by saying that the patient could not hear her, leaving her feeling upset, angry, and lacking trust and confidence in that nurse.

She described a nurse using strategies to build rapport by looking her in the eye and patting her on the shoulder. These strategies helped her to cope, to trust, and to feel confident. She described one nurse demonstrating impatience when the patient was agitated and restless, saying, “we just can’t have this.” She described this same nurse as

being curt and condescending to her when she called on the phone, causing her to feel like she was a bother. She expressed distress and lack of trust in this nurse; however, she expressed that knowing that other nurses were watching over this nurse helped her to cope and feel confident that her husband would receive the care he needed.

She described nurses providing her information by answering her questions and describing positive findings. She expressed that she did not want the nurse to tell her “he is not going to make it.” Avoiding prognostication allowed her to maintain some hope.

She again described the nurses using strategies to support her decision-making by hinting at the prognosis, which allowed her to maintain hope while still being able to prepare herself and her family for the possibility of death. After the patient had pulled out his arterial line when agitated, one nurse hinted at the trade-offs inherent in treating agitation and respiratory distress.

#### **4.5.2.4 P11 Third interview: Wife**

The third interview occurred on day 12 of the ICU stay. The wife again described the nurses bending the rules and assuring the comfort of the patient. She described feeling frustrated at one nurse who was rigid about the visiting hours:

[That nurse] sticks right by the rules; two people, he/she doesn't bend the rules any. And we'd both like to see him/her just relax. It's just the two of us, we're not bothering anybody, we're not loud, we just want to sit with him. But he/she, kicks us out, 'you got to go.' ...We want to be with him. I mean if our time is

limited, we want to be with him every minute we can be with him. And he/she knows how critically ill he is...I would like to, just like right now, I don't have anywhere to go, anything to do for two and a half hours, why can't I sit there quietly on my lap top? He's not going anywhere, he's not getting any, you know, nothing major's going on with him. I just want to be there. But, I can't. (Wife of P11, Third Interview, Day 12)

The wife described the nurses using strategies to build rapport by encouraging her to call anytime and to demonstrate professionalism by collaborating with their physician colleagues to assure that the patient was comfortable.

She described the nurses providing information by telling her the ventilator settings and laboratory results, explaining what the numbers meant, and by answering her questions. She expressed appreciation for the nurses not giving their "personal opinion," preferring to hear just the facts and interpreting those facts for herself. She again expressed appreciation for hearing positive findings. She expressed that these strategies helped her to cope and to maintain some hope.

Although she did not want nurses to share "personal opinions" and favored hearing positive findings, she also again described some nurses hinting at the prognosis. One nurse talked with her about quality of life. When a nurse compared the patient's condition from day to day, it helped her to realize that he was not getting better and to accept and prepare for his death. She described feeling in limbo when a nurse expressed uncertainty:

She said, 'you can't really ever tell. Everyone's so different.' So, she kind of said

she didn't think it looked good, but then she said, 'I've been totally wrong at times. So, you can't put any stock in what I'm telling you because you just don't ever know.' It feels like life's in limbo. You're not moving forward, you're not moving backwards. Until something, either gets a setback or he comes off the vent and flies. So, but we are still hanging on to that little bit of hope. But I, it's like I told my kids, 'even if he pulls through this one, there's just another one just around the corner.' You know, he's just sick, he is that...he's sick.

The wife's perceptions of strategies to demonstrate concern remained the same over the trajectory of the ICU stay. She noted lack of concern from one nurse at the second and third interviews. She described strategies to build rapport at all three interviews; at the second interview, she noted several strategies that were barriers to building rapport. At all three interviews, she described strategies to deliver factual information and expressed appreciation for hearing positive information without personal opinion. She also described nurses hinting at the prognosis, which helped her to prepare for the possibility of death. Figure 4 illustrates the trajectory of strategies.

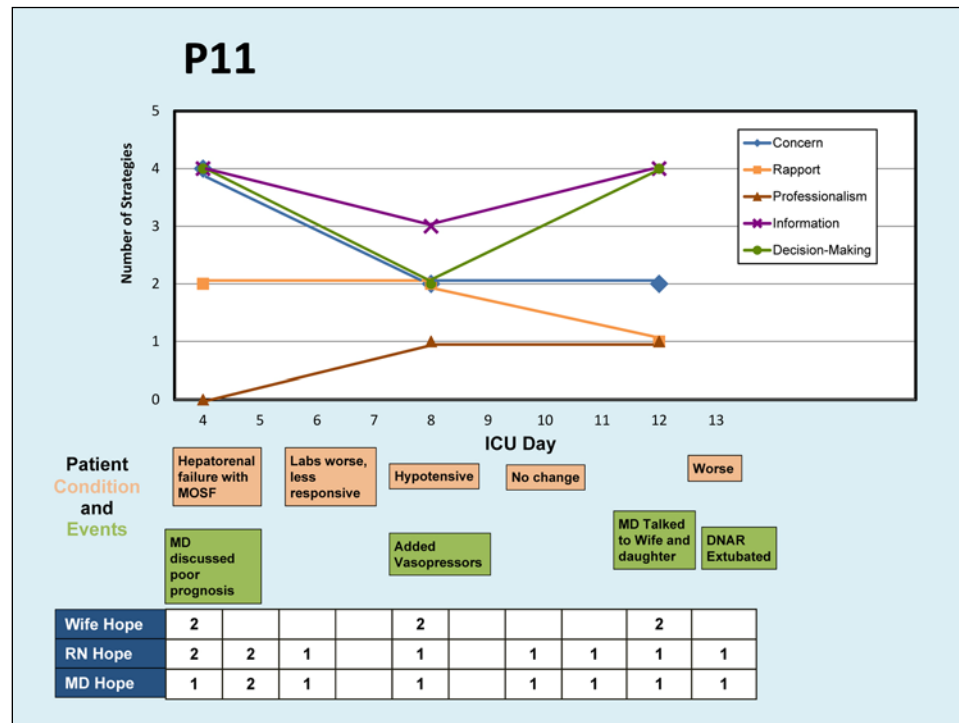


Figure 4: P11 Trajectory of Strategies

### 4.5.3 Trajectory P12

#### 4.5.3.1 P12 Description of Patient Illness Trajectory

The patient was a 65 year old African American male diagnosed with stage IV lung cancer one month prior to hospitalization. Three days prior to enrollment in the study, he was admitted to the ICU on a mechanical ventilator from the emergency department after experiencing respiratory failure. On day four of his ICU stay, he removed his own endotracheal tube. He remained off of mechanical ventilation for



several days. On day seven the attending and fellow met with the family in the patient's room. During this meeting when the attending physician suggested that it might have been better had the family not brought the patient to the hospital, the daughter became angry and left the room. The attending physician continued to talk to the wife about the goals of care. He recommended that the care be focused on keeping him comfortable, suggesting that he not be placed back on the ventilator if he should experience respiratory failure. The wife appeared to listen intently to what the attending physician said, nodding her head periodically. At the end of the meeting the attending physician wrote an order for a DNR. The following morning, when the family discovered that a DNR order was in place, they expressed anger and distrust of the attending physician who had written the order, saying that they had not authorized the order. They requested that he be a full code. The new attending met with the family and encouraged them to consider what the patient would want if his condition were to deteriorate. On day nine, the attending met with the family in the patient's room and asked the patient what he wanted. The attending told the patient that his disease was not curable and that the ventilator would not help him. The family requested that the meeting be terminated. On day 12 the patient was re-intubated and placed back on the ventilator for respiratory failure. On day 15 the attending again met with the family to discuss goals. The patient was discharged from the study at day 17 because he had been enrolled for a period of

two weeks. The patient was still on mechanical ventilation at that time and was still a full code.

**Table 16: P12 Illness Trajectory**

	ICU Day 3	ICU Day 6	ICU Day 7	ICU Day 8	ICU Day 9	ICU Day 12	ICU Day 15	ICU Day 17
Condition	Stage IV lung cancer. Vent No pressors	BiPAP/Nasal cannula Delirious	BiPAP	BiPAP	BiPAP 100%	Respiratory failure. Back on vent	Unchanged	Unchanged
Contextual Events	40	Self-extubated last evening	Family meeting in room with attending and fellow. DNR	Family upset about DNR. New attending met with wife and daughter.	Family meeting in room with patient, asking patient about wishes. Family terminated meeting	Family meeting last evening. Terminated by daughter		
Interview	Wife and daughter			Wife				Wife
Wife Hope	5			3.5				3.5
Daughter Hope	5							
Nurse Hope	1.2	1.2	1	1.2	1	1	1.1	2
MD Hope	2	1.5	1	1.1	1	1	1	1

Note: Pressors = Vasopressive Medication  
Vent = Mechanical Ventilator

#### **4.5.3.2 P12 First interview: Wife and daughter**

The wife and daughter were interviewed on day three of the ICU stay. Overall they were very pleased with the nursing care and described many strategies used by the nurses in all five categories. They described nurses using strategies to demonstrate concern for the physical well-being of the patient and family by assuring the patient's comfort, suggesting that the patient needed to rest, and providing for the comfort of the family members by offering them a chair. The family described the nurses as being empathetic and compassionate in the body language and speech they used when providing care, by talking to the patient in a soothing voice, and by bending the rules to allow them to visit more often. Their spiritual needs were acknowledged when the nurse allowed them to place a prayer blanket over the patient and encouraged them to pray. They expressed trust and confidence in the nurses as well as an ability to cope and to have hope. The support of their faith allowed them to continue to base their hope based on a strong religious faith that their loved one would survive. In addition, the strategies demonstrating concern supported a hope that the patient and family would be treated with care, compassion, and respect.

The wife and daughter also described several strategies that helped to build rapport and a sense of personal connection with the nurses. They described the nurses as personable and willing to engage with them, taking time to listen to them, being

patient with them, encouraging them to call any time, and using humor to lighten the mood. All of these strategies helped them to cope with the difficult situation and to have hope and trust in the nurses.

Both the wife and daughter described the nurses as “very professional.” The wife described the nurse as being there for the patient. She described nurses treating her loved one with respect and dignity. She also described collaboration between nurses and physicians and among nurses by conferring with the physician and with the charge nurse about the patient’s treatment. All of these strategies helped them to cope and have hope by instilling confidence in the nursing care.

The family described the nursing staff giving them information by keeping them apprised of any changes in the regimen or condition; answering questions; and explaining routines, equipment, and tests. The wife expressed appreciation for hearing that the patient was doing better and that his vital signs were stable. They both expressed feeling informed, confident in the care, and hopeful. They also expressed trust that the nurse would give them the information they needed.

The daughter described one nurse discussing the trade-offs between treating pain with opioids and trying to wean from the ventilator, explaining that the opioids would sedate him. She expressed feeling reassured that the nurse was competent and thinking through decisions.

#### **4.5.3.3 P12 Second interview: Wife**

The second interview was held on day eight of the ICU stay, which was the day after the wife discovered that the patient had a DNR order. Although she was clear that her anger was directed at the attending physician and not the nurse, she focused most of this interview on her distress over this incident. She expressed confidence in the nurse, whom she described as appearing very competent, assuring that the patient was comfortable, and explaining treatments and routines. She described experiencing some difficulty coping when she found out from the nurse that the patient had a DNR order and when she discovered that that her husband was not receiving any enteral nutrition. Finally, the wife described the nurse discussing trade-offs of comfort versus sedation and hinting at the prognosis by saying that the main goal was comfort. She expressed that these strategies helped her to feel informed and would help her with making decisions.

#### **4.5.3.4 P12 Third interview**

The wife was interviewed for the last time on ICU day 17. She described nurses using strategies to demonstrate concern by providing comfort to and talking to the patient. She described a nurse using strategies to build rapport by being patient with the family members as they asked questions, by showing respect, and by listening to them. She described the nurses giving information by answering questions but noted that one

nurse failed to keep her apprised of the patient's condition; the patient had removed his own endotracheal tube, and the nurse did not call to tell the wife. She expressed that she would have liked to know that but appreciated that the nurse apologized. Finally, she described the nurses using strategies to support her decision-making by accepting her decisions and not repeatedly reminding her how sick the patient was.

As in P5, the strategies in this case varied over time, particularly in the categories of providing information and supporting decision-making. Early in the ICU stay, the family described nurses giving positive findings and keeping them apprised of changes in condition or regimen, whereas later, the family noted two instances where the nurse did not keep them apprised of these changes. Whereas in the first and second interviews the nurse supported decision-making by talking about the trade-offs and by hinting at the prognosis, by the third interview, after the family had experienced several conflicts with the physicians, the nurse's approach was to support the family by demonstrating acceptance for their decisions. See Figure 5 for a graphic of strategies.

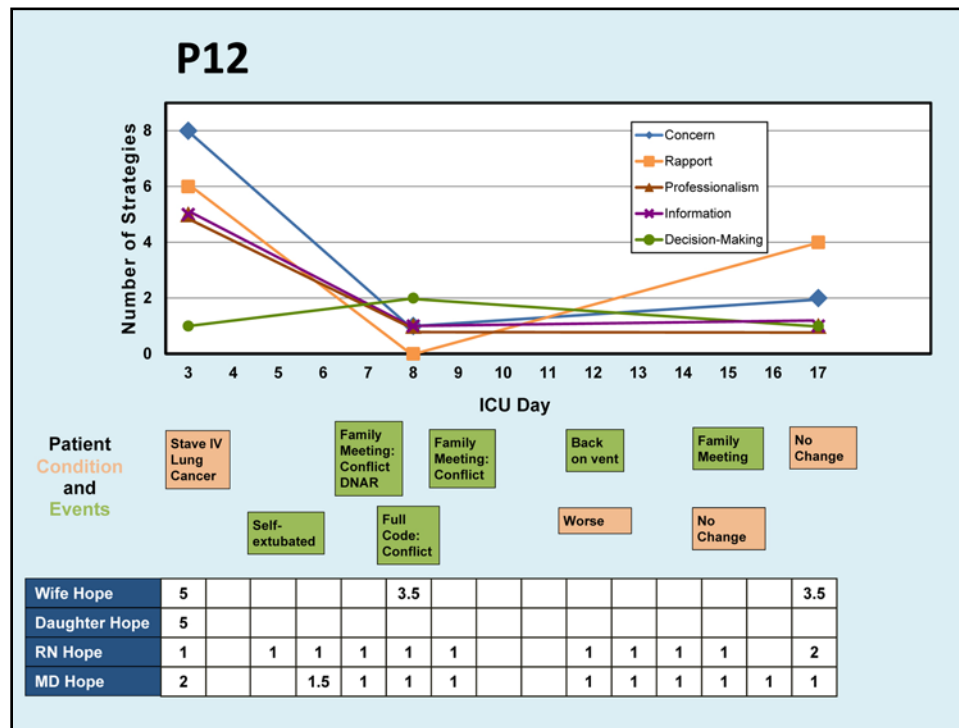


Figure 5: P12 Trajectory of Strategies

#### 4.5.4 Trajectory P13

##### 4.5.4.1 P 13 Description of patient illness trajectory

The patient was a 78 year old Caucasian male who was admitted to the hospital eight days prior to enrollment with pain and agitation. He was diagnosed with Guillain-Barre syndrome and transferred to the neurology floor where he had an episode of aspiration requiring intubation and transfer to the ICU for mechanical ventilation. He had a past medical history of coronary artery disease, repair of an abdominal aortic



aneurysm, hypertension, prior transient ischemic attack, morbid obesity, and sleep apnea, and bladder cancer status post bladder resection.

He was enrolled in the study on day three of his ICU stay and was on mechanical ventilation. Later that afternoon he was stable enough to have his endotracheal tube removed and did quite well off of mechanical ventilation for several days. He had a swallow study that showed that he was unable to swallow without risk of aspiration requiring a nasogastric tube for nutrition. He had pain and severe agitation that were difficult to manage.

Early in the morning of ICU day eight, an episode of aspiration required that he be re-intubated and placed back on mechanical ventilation. He also had an episode of sustained ventricular tachycardia. The fellow talked with the family about long term goals and the possibility that he might recover from this episode but continue to have repeated episodes of aspiration. He encouraged the family to talk among themselves about goals and scheduled a family meeting for the following day.

On day nine, the patient had an episode of asystole and was on norepinephrine to maintain his blood pressure. On day 11 the patient remained on mechanical ventilation and continued to experience agitation. The family and the interdisciplinary team convened for a meeting to discuss the goals of care. The family all agreed that the patient would not want to be on prolonged mechanical ventilation and that they wanted

to preserve his personal dignity. The mutual plan was to first optimize the treatment of the patient's pain and agitation and then to remove the endotracheal tube with the hope that he would do well but with the agreement that they not re-intubate him if he experienced respiratory failure ("one-way extubation").

On day 12, his sedatives were decreased enough that he was able to have the endotracheal tube removed the next day. The patient continued to improve on the regimen. On day 15 the patient was transferred to the step-down unit. This patient was the only one of the five trajectory analysis patients who survived that ICU stay. See Table 17 for summary of the illness trajectory.

**Table 17: P13 Illness Trajectory**

	ICU Day 3	ICU Day 4	ICU Day 6	ICU Day 8	ICU Day 9	ICU Day 11	ICU Day 12	ICU Day 14	ICU Day 15
Condition	Guillian-Barre syndrome, aspiration pneumonia	Nasal cannula	Nasal cannula	Vent 1 Pressor	Vent 1 Pressor	Vent	Vent	Off Vent	Off Vent
Contextual Events	Extubated in afternoon	Pain and agitation. Failed swallow study	Altered Mental Status Haldol drip	Aspirated V. tach. MD talked to family	Episode of asystole	Family meeting.		Extubated.	Transfer to step down unit.
Interview	Wife Daughter1				Daughter1 Daughter2		Daughter2 Daughter3		Wife
Wife Hope	4								4
D 1 Hope	3				1/2				
D 2 Hope							2/5		
D 3 Hope									
Nurse Hope	4.5	2		3	1.3	1.8	3.5		4.9
MD hope	3	3.3		2	2.2	1.6	1.6		4.5

Note: Pressors = Vasopressive Medication  
Vent = Mechanical Ventilator

#### **4.5.4.2 P13 First interview: Wife and first daughter**

The wife and Daughter1 were interviewed together on ICU day 3. They described nurses demonstrating concern for the patient by talking to him and assuring that his pain and symptoms were treated. They described nurses demonstrating concern for the family by bending the visitation rules and reassuring them that the patient would receive excellent medical and nursing care.

They described the nurses using strategies to build rapport by listening to them, encouraging them to ask questions, and using small talk. These strategies instilled confidence in the expertise of the care and trust that the nurses cared about the patient and family. The wife said, "You felt like you had a buddy. And I said, 'you're an angel.'"

The family expressed confidence and trust in the nurses, whom they described as very professional and competent. They noted that the nurse demonstrated a sense of higher duty to the patient and family by being astute and attentive to the patient's needs and respectful of the family and patient. They compared this to past experiences with nurses who were perceived to be chatting in the hallway about non work related issues while avoiding patient care. They also noted that the nurses demonstrated professionalism by collaborating with their physician colleagues.

The family described the nurses as very forthcoming with information, answering questions; explaining the routines, equipment, and treatment plans; and

using lay terminology. The wife expressed an appreciation that the nurses and physicians were just giving her the facts and focusing on what could be “fixed,” saying:

And at that point I will be asking someone, ‘what can I expect? What’s the future.’ But right now for me that’s not the important thing; right now it’s getting him well now...I want him to get well, and I want him to get the best care he can, and then I will face whatever, the future... Well they’re keeping me informed as to his heart rate, how his heart is doing, how his blood pressure’s doing, is he running a fever now, is his pneumonia getting better. Right now, I’m just taking it one step at a time and saying, ‘fix this, fix that next, and then we will talk about what’s in the future.’

Whereas the wife wanted to focus only on what could be done to “fix” the problems, the daughter described initiating a conversation with the nurse about the patient’s quality of life and whether his will to live affected his ability to overcome his medical issues. She indicated that this conversation helped to prepare her for what might occur.

#### **4.5.4.3 P13 Second interview: First and second daughters**

On day nine of the ICU stay, I interviewed Daughter1 and Daughter2. They identified several nurses in whom they had trust and confidence and contrasted these nurses with two nurses with whom they were very dissatisfied. They described the nurses whom they trusted as using strategies to demonstrate concern by bending the rules for visiting hours and to build rapport by encouraging them to call or ask questions, giving them a hug, and engaging in small talk. They expressed that these strategies helped them to feel a personal connection with these nurses and to have trust

and confidence in them. Daughter1 said, “You feel comfortable and confident that they’ve got your back, and they care about my father.”

The daughters described nurses using strategies that demonstrated professionalism by collaborating, by being cognizant of their role and scope of practice, and by being objective. They described nurses collaborating by pitching in to help other nurses in a crisis and speaking up in interdisciplinary rounds. Daughter2 expressed appreciation that the nurses did not “overstep” the bounds of their scope of practice and that the nurses were able to be objective and not inject their own personal issues in to the conversations with the family members. These strategies made them feel confident that their father was receiving competent care and to trust that the nurses would be supportive of them.

The daughters described nurses providing information by keeping them apprised of the changing condition of the patient, answering questions, explaining treatments and equipment, and using lay terminology. They also indicated that they relied on the nurse to interpret what the doctor said into language that they could understand:

And I said I’m okay, [Nurse L]’s here; I know that she’ll be that bridge to me. She understands what you guys are all talking about, and she’s the one that’s going to bring it down to the kindergarten terms that I need. I don’t want to waste your time with that. And I felt confident and comfortable that [nurse L] was competent in translating that to my terms.

These strategies instilled a sense of trust that the nurses would keep them informed and helped them to cope.

They contrasted these positive experiences with a nurse whom they perceived was avoiding patient care and acting in an unprofessional manner:

And here he is, he's having extreme trouble breathing, the rattle, and I was jumping up and down trying to suck it out of the back of his throat. He was sweating profusely, and his temperature had gone up a little bit, and [the nurse] said 'oh you can put a wet rag on him if you'd like.' [I thought] 'What the [expletive] are you getting paid to do?' And then we're sitting there doing this [putting a wet cloth on the patient's forehead], and he/she's turned her back talking to the nurse next door. And my anxiety and temper went out the roof. And I looked at my husband and said 'what the hell is going on here.' Really, all of the other nurses have kept their eyes on him. And I'm watching the clock twenty minutes later they're still chit-chatting about transfers, job openings, this that and the other.

They described a different nurse who they perceived was curt and avoided engaging with the family. Their response to this nurse was lack of trust and confidence and difficulty coping:

I was like 'dear Lord please I've got to leave this place, and I don't want to leave it.' And I came home, and I said 'mom I do not have a good feeling, something's wrong, something's wrong,' and sure enough, overnight is when he got in trouble, and they had to re-intubate him. So the fact that he had to be intubated that morning does not surprise me at all.

#### **4.5.4.4 P13 Third interview: Second and third daughters**

On day 12 I interviewed Daughter2 and Daughter3. This interview occurred the

day after the family meeting was held to discuss goals of care. The daughters described the nurse that day as being compassionate and in tune with what the family needed, listening to the family members; acknowledging their feelings; and knowing when they needed a hug, a pat on the shoulder, or an empathetic look. They also described the nurse going beyond regular duties by attending the family meeting and by doing extra things for the patient's comfort. They expressed how the nurse treated their father with dignity and respect, saying, "He wasn't just an object laying there; he was a person, and he was our daddy, and he/she seemed to relate to that..." They expressed confidence that the nurses would collaborate with the physicians to assure that their father had adequate pain management. This confidence allowed them to reframe their hope from hope for cure to hope for comfort. The daughters expressed how important these strategies were in supporting them and helping them to cope so that they were able to make decisions. They expressed trust and confidence in the nurse, which allowed them to feel confident that when they left, they were leaving their father in good hands.

#### **4.5.4.5 P13 Fourth interview: Wife**

The wife was interviewed on day 15 of the ICU stay. She described the nurses using strategies to demonstrate concern for the comfort and well-being of the patient by turning, changing bedding, and providing mouth care as well as concern for the wife's well-being by suggesting that she seemed tired and should go home and get some rest.



She also expressed comfort that the nurses would give her a hug when she needed one. She described the nurses using strategies to demonstrate professionalism by being present with the patient to care for his needs and not engaging in “chit chat” with other nurses while at work. She related that the nurses were forthcoming with information, explaining the fluctuations in vital signs and other findings. She described the nurse engaging with her in discussions about what to expect if a tracheostomy were performed, including discussions about the patient’s goals for care and quality of life. She indicated that having this conversation with the nurse helped her to feel more comfortable with her decisions:

We ask a lot of questions of [Nurse L], and has he/she ever seen anyone, what happened, if they put the trache in, what does that mean? Will he be able to talk? And she explained you could put fingers over it, and they could say some words; she explained all that. The feeding tube, I said have you ever worked with patients that have had this done. And just hearing about what she had to say it was reaffirming to us...it seemed like she said something...I remember her saying she had worked with patients that had had this done. And she worked with him enough that she knew his, or confirmed with us, his degree of agitation when he...

Throughout the trajectory, these family members described ways that the nurses facilitated their transition from curative to palliative care. Although these strategies fluctuated across the trajectory, they described recurring themes of trust and confidence and improved ability to cope and make decisions when nurses demonstrated concern, built rapport, demonstrated professionalism, provided information, and supported

decision-making. In the final interview, after the decisions had been made, the wife described several ways that the nurses were able to provide support for her decisions allowing her to feel more comfortable with her decisions and to be prepared. See Figure 6 for a graphic of strategies.

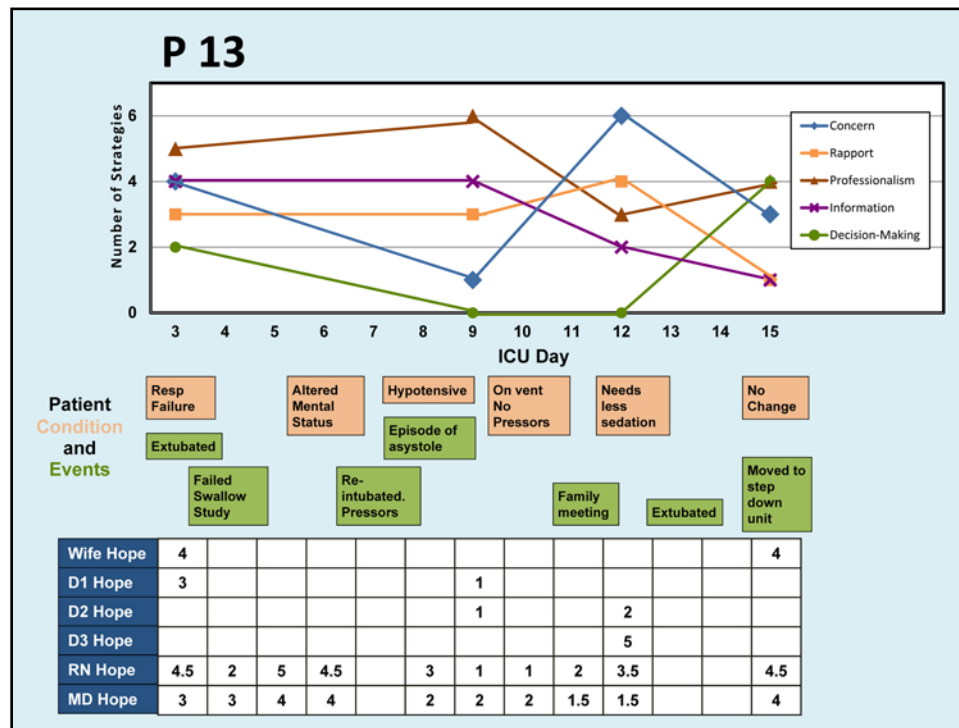


Figure 6: P13 Trajectory of Strategies

## 4.5.5 Trajectory P15

### 4.5.5.1 P15 Description of patient illness trajectory

The patient was a 59 year old African American female with right sided heart failure, pulmonary hypertension, pulmonary embolism, and acute kidney injury, who was admitted to an outside hospital 10 days ago. She had a cardiac arrest at the outside hospital requiring her to require mechanical ventilation. Although she was able to be weaned from mechanical ventilation, she required re-intubation 2 days prior to

enrollment. She was transferred to the medical ICU at Duke Hospital the day before enrollment.

On the day of enrollment, the patient had a cardiac arrest requiring chest compressions, and her arterial blood gases were poor. She was on high ventilator settings and two vasoactive medications (dobutamine and norepinephrine) to maintain her blood pressure. The attending physician met with the daughter, explained the seriousness of the illness, hinted at the poor prognosis, and reassured her that the patient would receive excellent medical care. On day four, the patient had stabilized, but the prognosis remained poor. The physician team indicated to me that they were keeping the daughter informed but had not had any formal discussions and had not yet broached the topic of EOL care. On day six a progress note indicated a poor prognosis and high risk of mortality. On day eight I asked the attending if any discussion occurred with the family about goals of care; he replied that he had little hope for the patient's survival but did not want to broach the topic with the family because he did not know her well enough (he was covering for the weekend only). He said that he would leave it to the attending coming on service the following day.

On day 10 the healthcare team had not yet discussed goals of care or EOL issues. On day 11 the resident physician talked to the daughter about the poor prognosis. On day 12 the patient developed a fever, and an unsuccessful attempt was made to change

out the parenteral lines. On day 13 the patient was diagnosed with fungemia. The cardiologist agreed that the prognosis was grim. The fellow talked with the daughter about the need to change the parenteral lines to treat the infection. A nurse who had been caring for the patient over the previous several days told me that he/she and another nurse had approached the daughter and told her that the patient was very sick and would likely never make it out of the ICU. They said that they did not want to inflict pain on the patient by attempting to change out all the lines. A family meeting was held that afternoon with the entire extended family, several physicians, and the nurse who was caring for the patient. They mutually agreed to continue to treat her aggressively with antibiotics, mechanical ventilation, vasopressors, and continuous dialysis but not to attempt to change out the lines and not attempt CPR. On day 14, the ventilator was weaned down, but according to the attending physician, this did not change the prognosis. The nurse told me that he/she explained to the family that the kidneys and heart were not functioning, the lungs were not better, and that the endotracheal tube would need to be removed soon or it could cause damage. This nurse said that he/she described a "one way extubation" to the family. On day 15 the resident alerted me that a family meeting was scheduled for that evening to discuss "one-way extubation." When the resident and fellow met with the family the daughter was distraught and repeated "don't make me pull the plug on my momma." The fellow reassured her that they were

not asking her to do that. They confirmed that the patient was a DNR and reassured her that they would continue to treat her mother but did not want to cause her pain. See Table 18 for summary of the illness trajectory.

**Table 18: P15 Illness Trajectory**

	ICU Day 2	ICU Day 4	ICU Day 8	ICU Day 10	ICU Day 11	ICU Day 13	ICU Day 14	ICU Day 15
Condition	Severe pulmonary hypertension Poor prognosis. Vent 2 Pressors	Stabilized but remains poor	No change	No change	No change	Fungemia. Cardiologist agreed prognosis grim.	Vent weaned	Remains poor
Contextual Events	Coded this morning and needed CPR	Started nitrous oxide	Attending put off EOL discussion	No discussion of goals of care	Resident talked to daughter. Daughter upset, "Why are they giving up."	Family Meeting. Nurse said he/she did not want to inflict pain	DNR. Nurse discussed one way extubation with family	Family Meeting. Daughter distraught Don't make me pull the plug on my momma
Interview	Daughter			Daughter				Daughter
Daughter Hope	3			3				1
Nurse Hope	1.5	1	1.5	1.5	1	1	1	1
MD hope	2	2	1.5	2.5	1.5	1	1	1

Note: Pressors = Vasopressive Medication  
Vent = Mechanical Ventilator

#### **4.5.5.2 P15 First interview: Daughter**

The first interview with the daughter occurred on day two of the ICU stay at Duke Hospital. She described nurses using strategies that demonstrated concern for her by encouraging her to take care of herself, reassuring her that the skilled medical and nursing team would do the best they could for her mother, bending the rules to allow her to spend more time with her mother, and expressing empathy and compassion. One nurse at the outside hospital said to her, "This is your mom; I would be the same way with my mom." She also described nurses using strategies that showed concern for the needs of the patient by talking to her as they provided care and by changing her and turning her frequently. She expressed that these strategies allowed her to have hope that her mother would receive the best care available, to feel confident in the care, and to trust that the nurses cared about her, which in turn allowed her to get sleep for the first time in eight days. She also described a nurse at the outside hospital who was rough with her mother and rigid about visiting hours, contributing to feelings of distrust and difficulty coping.

She described the nurses using strategies to build rapport by acknowledging her, introducing themselves and other staff, listening to her, and being personable. This was in contrast to other nurses who were impatient and avoided engaging with her. The nurses whom she perceived as more personable instilled a sense of trust, whereas those



who did not engage made her afraid to ask questions and led her to question whether her mother was receiving good care.

The daughter described two very different experiences with nurses carrying out their roles as professionals. She described nurses who were an abiding presence versus those at the outside hospital whom she observed sleeping at their desk on the night shift. Her perception that the nurses at Duke Hospital would be an abiding presence watching over her mother allowed her to leave the hospital at night to sleep knowing her mother was under watchful eyes, whereas the experience of finding nurses asleep at the desk increased her anxiety and lack of trust and confidence:

Yeah, so I was like, 'wow, how was my mom being taken care of...oh yeah, I'm freaking out at this point. I'm really not going home now; I'm really staying in this room and watching everything they are doing, paying attention to her, making sure that her numbers aren't falling, that sort of thing. So, it just made my whole trust issue with them go up, like I really don't trust them to point of no return right now.

The daughter expressed that she did not need to ask questions because the nurses anticipated her need for information. She described the nurses keeping her apprised of the daily changes in regimen and treatment, explaining hospital routines, explaining what medicines were being administered and why, and explaining the meaning and acceptable range of numbers on the monitors. These strategies helped her to trust and to cope. She described experiences at the outside hospital of nurses who

failed to keep her apprised of her mother's condition and the treatment plan. This contributed to a lack of trust and confidence.

At the start of the interview, the daughter described a nurse explaining that her mother was very sick and that "anything could happen." She indicated that the other strategies in the categories of demonstrate concern, build rapport, demonstrate professionalism, and provide information allowed her to cope with hearing that her mother might not survive:

And they've been real nice; they haven't said or done anything that was not comforting to me. Even with them explaining how sick my mom is, and even knowing that anything can happen at this point, I just feel a lot better knowing that she is here.

#### **4.5.5.3 P15 Second interview: Daughter**

I interviewed the daughter on day 10 of her mother's ICU stay. She was very hopeful during this interview and perceived that she was being told that her mother was making progress and might be able to go home at some point.

The nurses continued to use strategies to demonstrate concern by reassuring her that her mother was receiving excellent care, encouraging her to take care of herself, and assuring that the patient was comfortable. In addition, she described the nurse reassuring her that the patient was stable, saying, "No worries she's fine, and she'll be okay. She is still stable right now, and there is no change, and everything is okay." She

described the nurses telling her that the patient might eventually be able to go home on a parenteral cardiac medication for pulmonary hypertension (epoprostenol/Flolan) that the daughter would have to learn how to administer. This concern and optimism helped her to feel confident and hopeful and improved her ability to cope. She described lack of trust in one nurse whom she perceived was avoiding patient care.

She described strategies that nurses used to build rapport including acknowledging her, engaging with her, encouraging her to call anytime, being patient with her, and being personable. These strategies helped her to feel comfortable asking questions, to feel confident in the nurses, and to cope. She described lacking trust in one nurse who avoided engaging with her.

She described nurses keeping her apprised of the patient's condition, giving positive findings and explaining treatments saying:

Well, they have been very good with letting me know, like how her blood pressure and everything is stabilized, and they tell me about the dosage of the medications, they let me know what meds they are giving her, and they let me know what they've done throughout the day.... They have been very informational as far as letting me know how well they are caring for her and how she is taking the meds.

Her response to this information was hope that her mother was "still holding on" and "could recover from this."

She described that, although the nurses and physicians reminded her that her

mother was still very sick, they reassured her that they were doing everything they could to try to help her recover. She remarked that what she was hearing fueled her hope that her mother would survive:

Well, I mean, they haven't said anything as far as her not making it. No one has said, 'anything could happen at this point;' no one is saying that. Like, 'anything could happen, like it's more of a 50/50, like before.' They are saying now she is progressing to recovery, so that makes me, that makes everything a little bit easier. So, I'm not looking more towards having to do funeral arrangements and that kind of thing; I'm more looking towards just preparing her to come home and taking care of her.

Although she expressed positive feelings about what she was hearing, these strategies might have contributed to her being unprepared for what occurred next. The day after this interview, the resident spoke to the daughter about the poor prognosis and possibility of having to make decisions about whether or not to continue to pursue aggressive care. The daughter responded with dismay. She told me that the doctors had all been telling her that her mom was making progress, and she didn't understand why all of a sudden they seemed to be giving up on her.

#### **4.5.5.4 P15 Third interview: Daughter**

The third interview occurred on day 15 of the ICU stay. The daughter had participated in two family meetings to discuss goals of care, and a DNR order had been written. The patient remained on life support. The daughter described one nurse using strategies to demonstrate concern for her by display his/her sadness and being tearful.

Other strategies included bending the rules, encouraging her to participate in the care of her mother, reassuring her that the patient would continue to receive excellent care, and acknowledging her faith. In addition, the daughter described the nurse validating her love and concern for her mother: “he/she kept saying ‘don’t beat yourself over this’ and letting me know how good of a daughter I was and how I stood by mama’s side.” She indicated that these strategies instilled trust in the nurse and helped her to cope and to accept that her mother was dying. She expressed lack of trust and confidence in one nurse who was rigid with the visiting hours.

The daughter described the nurse using strategies to build rapport by engaging with the family and encouraging them to show pictures of her mother. She described feeling a personal connection with this nurses and feeling that this nurse was someone that she trusted really cared about her and her mother. She described another nurse being curt with her; although this nurse apologized, she remained dubious about his/her level of empathy and concern for her and her mother.

The daughter expressed appreciation for the nurse keeping her apprised of the patient’s condition and giving her positive findings, such as telling her that the patient moved her toes and that the blood pressure was stable. These strategies helped her to cope.

The daughter also described two particular nurses with whom she felt a personal

connection and rapport as being the two who engaged in discussions with her about EOL decisions. She described several strategies used by these two nurses to support her decision-making, including being honest, describing the severity of the illness, saying that the patient was unlikely to survive, discussing options for treatment, consequences of decisions, saying that they did not want to inflict pain on the patient, and reframing hope from hope of cure to hope for peaceful death. She noted the difference between the information from the physician, which was factual, and that from the two nurses, which included more detail about how the treatments would affect her mother:

The doctor came out he was like, 'this is what we're going to do; we can completely get rid of the infection, but we're going to have to change these lines out.' That's basically what he said flat out; he didn't say nothing about the pain that she was going to be in or anything; he didn't say about her blood pressure dropping-he did say that there could be some risk of something could happen, but he didn't go into detail like [nurse] did. He didn't say like this is going to hurt her the way they did. And I didn't want-I didn't want that.

These strategies helped the daughter to maintain hope that she and her mother would continue to be treated with compassion and respect, to reframe her hope from hope of cure to hope of peaceful death, to cope, to accept, and to make decisions.

The daughter identified strategies in the categories of demonstrate concern, build rapport, and provide information in all three interviews. The decision-support strategies in the first interview were indirect, involving description of severity of illness and uncertainty. At the third interview, after two family meetings, the opportunity to build

rapport with two nurses, and certainty from the perspective of the HCPs that the patient had no hope of survival, the nurses were more actively involved in decision-support. See Figure 7 for illustration of the trajectory of strategies.

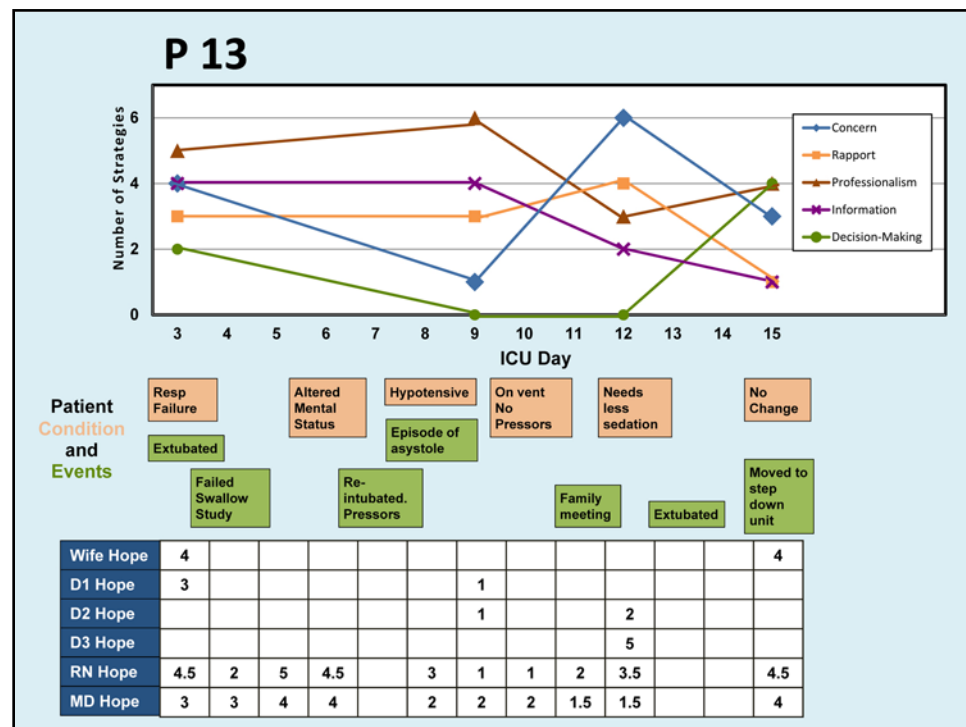


Figure 7: P15 Trajectory of Strategies

## **4.6 Discussion**

To my knowledge, this study was the first to follow family members prospectively and longitudinally in an ICU environment over the trajectory of transition from curative to palliative care to explore how they perceived and responded to nursing strategies. I identified five approaches to providing support to family members: demonstrate concern, build rapport, demonstrate professionalism, provide information, and support decision-making. These approaches were linked to family member responses. The findings support data from a systematic review of the nursing literature indicating that family members rely on nurses as they navigate the difficult transition from curative to palliative care (Adams et al., 2011). These findings add to the existing literature by identifying specific strategies from the perspective of the family members, how these strategies were helpful or unhelpful in navigating this transition, and how these strategies changed over the trajectory of the transition from curative to palliative care.

### **4.6.1 Demonstrate Concern**

Nurses have asserted that by enacting the role of supporter for family members, they are able to facilitate the transition from curative to palliative care (Adams et al., 2011). The findings from this study provide empirical evidence for this assertion by



identifying an approach of demonstrating concern for the well-being of the patient and family member. The family members described specific strategies and how they perceived these strategies as helpful or unhelpful. The participants in this study expressed that strategies indicating an approach of demonstrating concern for the patient, such as providing gentle personal care and talking to the patient, helped them to have confidence in the nursing care and hope that their loved one would be treated with compassion. Strategies that demonstrated concern for the emotional well-being of family members, such as being optimistic, reassuring, empathetic, and acknowledging their feelings, allowed them to trust that the nurse would be present to guide and support them on their journey and helped them to cope with the stressful ICU environment. Family members indicated that this ability to cope helped them to make decisions.

Family members especially appreciated nurses who demonstrated concern for the emotional well-being of the family member by having a positive outlook and being optimistic. These strategies supported their hope, including hope that their loved one would receive excellent care, hope that their loved one would survive, and hope that they and their loved one would be treated with care and compassion.

A frequently identified strategy to support the psychosocial well-being of family members was a nurses' willingness to bend the rules for visiting hours. Although the literature suggests that family members as well as patients benefit from more flexible

visitation in the ICU (Sims & Miracle, 2006), most ICUs in the United States continue to have restrictive visiting policies (Lee et al., 2007; Liu, Read, Scruth, & Cheng, 2013). The findings from this study support that family members benefit from more flexible visiting hours. The participants in this study were very vocal about their need to be with their loved one, especially as it became more evident that the patient might not survive, and expressed that being allowed to visit more freely and allowing their family to be together as a family unit helped them to cope and to trust that the nurse cared.

The nursing literature about EOL care in the ICU describes many ways that nurses demonstrate concern; however, this literature does not describe nurses using strategies that demonstrate a lack of concern. The findings from this study indicate that family members perceived some nurses engaging in ways that demonstrated lack of concern and that these behaviors had a devastating effect on the family members' ability to cope. Some of the ways nurses demonstrated lack of concern included, being rough with the patient, being impatient with the family, being blunt, or avoiding patient care. Several family members expressed dismay when nurses were rigid about the visiting hours, allowing only two visitors at a time and restricting the hours to the posted times. Although the visiting restrictions were lifted once a family member had made the decision to withdraw life support, if a family member had not made that decision, the visiting hours were sometimes enforced, even when it was clear that the patient was not

likely to survive. This meant that family members, who understood that their loved one was likely not to survive but were not ready to stop aggressive treatment, were sometimes forced to be separated from their loved one for long periods of time. Although the participants in this study did not verbalize feeling judged by this rigidity in the visitation rules, it could be interpreted that the family members were being penalized for making the wrong decision. When family members described nurses using these approaches that demonstrated lack of concern, they expressed anxiety, anger, lack of trust, dissatisfaction, and difficulty coping.

The findings from this study provide empirical evidence to support that an approach that demonstrated concern for the well-being of the patient and family members helped family members by instilling trust and confidence and by helping family members to cope and maintain hope. The ability to cope and have hope helped family members to feel prepared to make decisions. Further, these findings provide evidence that approaches demonstrating lack of concern negatively affected the family members' ability to trust and cope.

#### **4.6.2 Approach: Build Rapport**

Because ICU nurses are at the bedside with patients for entire shifts, they have a unique opportunity to build rapport with the family members. Nurses report that a rapport building approach helps family members transition from curative to palliative

care (Adams et al., 2011). Family members report that the strong bonds they develop with nurses foster trust and confidence and help them to navigate the process of transition from curative to palliative care (Fry & Warren, 2007; Limerick, 2007). This current study added evidence to support these findings. Family members reported that when nurses used strategies to build rapport, family members felt a personal connection with the nurse, felt comfortable asking questions, trusted the nurse, felt confident in the care, and were better able to cope with the stress of the ICU environment.

In some cases, the trusting relationships that were established using strategies to build rapport facilitated the nurses' ability to engage in discussions about EOL decisions. Two examples are the wife of P5 and the daughter of P15, both of whom described a very close connection with a nurse whom they identified as someone who really cared. Each of these family members described receiving support for their decision-making from a nurse that they perceived as helpful, whereas they viewed the same information from other health care providers as not helpful.

Approaches to build rapport as well as strategies to demonstrate concern provided support for family members' hope. Although hope is often defined in terms of a desirable outcome, such as cure, prolongation of life, or a peaceful death, hope might also be based on the perception of having someone to trust and rely upon to provide support and care (Tulsky, 2002). In this study family members described specific

strategies that nurses used to reassure them that the patient was being cared for and that they (the nurse) would be there for them and for the patient through the journey, providing comfort and care, no matter what the outcome.

The literature suggests that nurses are not always successful in building rapport with family members. Qualitative researchers in Spain observed ICU nurses who failed to introduce themselves, avoided eye contact, and spent much of the time performing tasks with their backs to the family members (Zaforteza et al., 2005). Ethnographic researchers studying ICU nurses in Australia indicated that a therapeutic engagement of nurses with the family was missing (Sorensen & Iedema, 2007). The data from this study support these findings. Family members described nurses whose approach demonstrated a lack of rapport building. The participants described nurses who did not make eye contact; turned their back on the family; or were impatient, curt, or dismissive with patients and family members. When family members experienced a nurse who demonstrated these behaviors, they expressed dissatisfaction, difficulty coping, and lack of trust and confidence in the nurse.

The findings from this study provide empirical evidence that when nurses used an approach to build rapport, family members were able to develop trusting relationships with nurses and felt they were better able to cope. In addition, this approach facilitated the ability of the nurse to participate in EOL discussion with the

family members. Family members reacted strongly to approaches that demonstrated a lack of attempt to build rapport, such as avoiding eye contact, turning their back to the family, and communicating a lack of attempt to draw the family in. The family members who perceived this approach expressed lack of trust and confidence and difficulty coping.

#### **4.6.3 Approach: Demonstrate Professionalism**

Nurses support family members of ICU patients by using an approach that demonstrates professionalism. The nursing literature identifies several strategies in this approach, including being present with the patient; collaborating and coordinating with other professionals; scheduling, attending, and participating in family meetings; mediating; advocating for the patients and family members (Adams et al., 2011); and being respectful of the patient and family members (Belanger, 2008).

The participants in this study described three approaches to demonstrating professionalism, including demonstrating a professional demeanor, demonstrating cognizance of their scope of practice, and remaining unbiased. Participants in this study indicated that nurses demonstrated professional demeanor by being calm, appearing competent, demonstrating professional ethics and a sense of higher duty to the patient and family members, having a positive morale, expressing confidence in the plan, giving consistent information, and respecting the patient's confidentiality and dignity. Family

members also expressed that, although they wanted to feel a personal connection with their nurse, they also expected that the nurse would not interject his/her own personal problems into discussions. Family members found comfort in what they saw as professionalism in the nurses who were caring for their loved ones, expressing that these strategies helped them to cope, to have confidence in the care, to trust the nurse, to feel comfortable asking the nurse questions, and to have hope.

Nurses enact their roles within a defined scope of practice. This scope of practice includes when and how nurses should engage with family members about EOL decision-making. The literature indicates that the approach to discussions about prognosis and EOL decisions varies widely among nurses (Adams et al., 2011). As nurses navigate their role as advocates, they are sometimes challenged by lack of clarity about their scope of practice (Reinke et al., 2010) and lack of support from their physician colleagues and the culture of the ICU (Baggs et al., 2007). Many ICUs have unwritten rules that discourage nurses from engaging in EOL discussions with family members (Baggs et al., 2007), and nurses report being left out of the decision-making process (Sorensen & Iedema, 2006). Other nurses do not attempt to engage in the process (Sorensen & Iedema, 2006; Todd et al., 2005). Some nurses perceive that discussing EOL issues, especially prognosis, is outside of the scope of their professional practice (Reinke et al., 2010). Others report engaging in these discussions only after the physician has

broached the topic (Gutierrez, 2010; Kirchhoff et al., 2000; Reckling, 1997). Still others initiate discussions about EOL issues, going against the unwritten rules, because of an ethical imperative to be honest with a family member, especially if they perceive that aggressive care is prolonging the dying process and causing suffering for the patient and family members (Calvin et al., 2009; Robichaux & Clark, 2006). Findings from studies of family members of ICU patients indicate that these family members want information that is consistent (Nelson, Puntillo, et al., 2010; Norton, Tilden, Tolle, Nelson, & Eggman, 2003) and that they look to the physician for medical decisions and discussion of the prognosis (Apatira et al., 2008; Belanger, 2008). However, some family members have also expressed appreciation for nurses who gave them clear prognostic information, affirmed their decisions, and helped them with “personal” decisions, such as whether to try to take their loved one home (Belanger, 2008). In a recent retrospective study of family members in an ICU in Norway, the participants expressed frustration when they described the nurses as being vague and evasive when they asked about the prognosis; they assumed that the cause for the evasiveness was because such discussions were not within a nurse’s scope of practice (Lind, Lorem, Nortvedt, & Hevroy, 2012).

In this study, few participants described nurses engaging with them in discussions about EOL decisions or prognosis. Several family members said that they appreciated nurses who did not “overstep their bounds” by giving a “personal opinion”



about what they would do or saying that they did not think the patient would “make it.”

Others reported that nurses told them that nurses were not allowed to discuss the prognosis with them. Some of the participants perceived that the nurses avoided EOL discussions by being vague, giving meaningless information, and not addressing the issue that the patient was clearly dying. One family member expressed frustration at what she perceived as vague information leaving her “in limbo.” Another family member described a nurse telling her that the patient would likely die that night. Although she expressed appreciation for the nurse giving her that information, she perceived that this nurse might have overstepped his/her bounds, asking me to please not say anything to get this nurse “in trouble.”

The family members in this study indicated that they preferred prognostic information to come from the physicians. However, once the physician had disclosed the prognosis, the family members appreciated the strategies the nurses used to help them to interpret the meaning of this information. One family member described the nurses explaining the meaning of the decision whether or not to escalate care by explaining that the patient would suffer and that the treatment would not affect the long term outcome. The nurses were able to help this family member make a decision by explaining the consequences of the decisions and helping her to reframe her hope from one of cure to one of comfort. The nurses were able to do this because of the strength of

the relationship they had with the family member.

Although nurses may engage in education and counseling of patients and family members independently of physicians, one of the tenets of professional nursing practice is the ability to advocate for the patient and family and to collaborate with their professional colleagues (ANA, 2010a). As important as it is that the family understand what is happening and are supported in making decisions, it is equally important that the message family members hear is clear and consistent (IOM, 2011; Nelson, Puntillo, et al., 2010).

The literature is rife with examples of gaps in communication about EOL decisions in the ICU (Hancock et al., 2007; Jackson et al., 2008; Kryworuchko et al., 2012; Limerick, 2007; Lind et al., 2011; Nelson, Puntillo, et al., 2010). Lack of communication, inadequate communication, and inconsistent communication are all sources of stress and conflict in EOL situations in the ICU (Abbott et al., 2001; Nelson, Puntillo, et al., 2010). Because nurses are present at the bedside for prolonged periods of time, they see the changing condition of the patients and the emotional state of family members and are therefore in a position to fill in these gaps by being leaders in facilitating communication and easing the transition from curative to palliative care in the ICU.

As part of enacting their professional roles, nurses are expected to assess the response of the patient to treatment as well as the family member's response to the

patient's illness, to assess the family members' needs and understanding of the illness and prognosis, and to provide education and counseling to help family members with the process of decision-making (ANA, 2010b). Although nurses are not the first to disclose the prognosis to family members, because of their presence with the patient and family members, nurses are often the first to see the "big picture" and to identify that a patient is dying (Liaschenko et al., 2009). As part of enacting their professional role, nurses bring information about their assessment of the responses of the patient and family members to the interdisciplinary team. Once the physician has disclosed the prognosis and discussed EOL decisions, nurses provide support, education, and counseling to family members to help the family members to understand what the prognosis means for their loved one and how the treatment decisions might affect the overall picture.

Nurses who are clear about their role and express this clarity to family members might help to fill in the communication gap and avoid confusion. When asked about prognosis, rather than saying, "I cannot talk about that, you have to ask the physician," the nurse might ask the family member to describe their understanding of the prognosis before discussing it further. This would help the nurse to determine what the family already knows and understands. If the family member has not been told the prognosis, it is appropriate for the nurse to defer to the physician and to let the physician know that

the family member is asking questions about the prognosis. However, if the family member has been told but is having difficulty understanding what this means for their loved one, the role of the nurse includes helping the family member to understand what the prognosis means for the patient. Nurses need to be present during family meetings as well as informal discussions between physicians and family members so that nurses know what the family members have been told. This will help the nurse to give information that is consistent with what the family member has already been told. By being clear about their role and scope, assessing the information needs of family members, and collaborating with their physician colleagues, nurses can help to close the information gaps and improve the overall delivery of EOL care in the ICU.

#### **4.6.4 Approach: Provide Information**

Nurses have been described as information brokers the ICU (Adams et al., 2011; Baggs et al., 2004; Jezewski, Scherer, Miller, & Battista, 1993). Nurses assert that they empower family members by providing information (Thompson et al., 2006) about the disease process (Murphy et al., 2001) and by interpreting, and clarifying information (Barthow et al., 2009; Calvin et al., 2007). Family members have indicated that they rely on the nurse for information about the ICU environment and equipment as well as updates on the patient's treatment, including the reason for treatments (Limerick, 2007; Verhaeghe, Defloor, Van Zuuren, Duijnstee, & Grypdonck, 2005). In addition, family

members have indicated that they trust that nurses will give them accurate information about how the patient is responding to treatment (Fry & Warren, 2007).

The findings from this study demonstrate that family members were hungry for information as they tried to cope and make sense of what was happening to their loved one. They recognized that because nurses were an abiding presence at the bedside of patients for long shifts, they saw the small changes and were a source of accurate, up to date information, and they relied on nurses for information on the day to day and even hour to hour changes in the condition of the patient. Family members relied on nurses to keep them apprised of changes by updating them when they arrived on the unit and when they phoned in during times when they could not be physically present. In addition, family members expressed that they relied on the nurse to interpret the information they received from the physicians, putting the information into lay language that they could understand. This access to up to date information helped them cope with the stress of having their loved one in the ICU. Family members were able to trust that the nurse would be a source of accurate information.

Along with information about the patient's condition and response to treatment, family members wanted to know why certain treatments were being delivered and the expected response to those treatments. Having nurses describe what they were doing and why they were doing it increased the family member's confidence that this was a

nurse who was really competent and experienced and knew what he/she was doing.

This in turn helped the family member to cope and supported their hope that their loved one was being cared for by a competent professional.

Although the participants in this study described nurses as valuable sources of information, they also described situations when nurses did not fill that important role. When family members described nurses who were unable to answer questions, who left them hanging, or who gave them accurate information, they expressed lack of trust and confidence and difficulty coping. Several family members described calling in at night for an update and being told to call back later; they related that the wait was excruciating.

#### **4.6.5 Approach: Support Decision-Making**

The literature describes numerous strategies used by nurses to support family members' decision-making during the transition from curative to palliative care.

Nursing strategies identified in the literature include: prepare family members for bad news, clarify and interpret what the physician has said, discuss the prognosis after it has been introduced by the physician, encourage family members to identify their values and goals, explain options and describe consequences of decisions, drop hints about the poor prognosis, explain that the patient is not responding to treatment, discuss quality of life, reframe hope from hope of cure to hope for peaceful death by emphasizing what

can be done, and accepting family member's decisions (Adams et al., 2011).

The literature from studies of family members suggests that nursing involvement in EOL decision-making might be correlated with increased satisfaction (Fox-Wasylyshyn et al., 2005), and that family members might be better able to understand the prognosis and able to accept that their loved one is dying when nurses are involved (Limerick, 2007; Lind et al., 2011). However, these studies provide little detail about the specific strategies that nurses used when they were engaged in the decision-making process. The findings from this study provide empirical evidence of specific strategies that family members find helpful in their ability to prepare themselves, to cope, to accept death, and to make decisions.

Although nurses have an array of strategies to support decision-making, the literature indicates that nurses do not consistently use these strategies and that nurses sometimes avoid involvement in the EOL decision-making process (Adams et al., 2011; Lind et al., 2011, 2012). Estimates of the extent to which nurses engage in discussion with family members about EOL decision-making vary from 50-80% (Adams et al., 2011). Further, the literature identifies several nursing behaviors that might be perceived as harmful by family members, such as pushing families to make decisions (Calvin et al., 2007), providing personal opinions (Calvin et al., 2007), telling family members that the patient is dying (Calvin et al., 2009), and encouraging family members to observe

treatments so that the family can see that the patient is suffering (Robichaux & Clark, 2006). Although the literature identifies several negative behaviors, it does not provide evidence of how family members respond to these strategies.

The findings from this study support that nurses are not consistently involved in EOL decision-making. Further, these findings indicate that some nurses engaged in behaviors that family members found disruptive and stressful, including giving personal opinions and demonstrating lack of support for their decisions. Only two participants related that a nurse told them directly that their loved one was dying. One of these participants appreciated being told that her loved one was dying, whereas the other found it upsetting. No participants described nurses telling them their loved one was suffering or intentionally encouraging them to observe procedures that caused suffering. One family member described how distressing it was to be present while her husband was being bathed because his vital signs became unstable; however she perceived that the nurse allowed her to stay out of concern for her need to spend time with her husband.

The trajectory analysis demonstrated that the use of the strategies to support decision-making varied over the trajectory. The findings indicated that nurses used these strategies more sparingly earlier in the ICU stay, using an average of two strategies at the first interview and less than one at the second interview. By the third or fourth



interview, the use of these strategies was higher, with an average of four. Three of the five trajectories (P5, P13, and P15) demonstrated an increase in the number of decision-support strategies by the third or fourth interview. In all three of those trajectories, the support for decision-making strategies increased after a physician had talked to the family member about the poor prognosis. This is consistent with the literature that suggests that nurses wait to use decision-support strategies until after the physician has broached the topic of a poor prognosis (Gutierrez, 2010; Reckling, 1997).

The other two trajectories (P11, and P12) did not demonstrate an overall increase in these strategies. Although the P12 trajectory did not demonstrate a change in the number of strategies, the nature of the strategies changed from discussing trade-offs and hinting at the prognosis early in the ICU stay to accepting the family member's decisions and refraining from reminding them how sick the patient was later in the ICU stay. In this case, the family member had experienced several episodes of conflict with the physicians over decision-making. These findings indicate that the nurses were responsive to the needs of this family member.

Family members of patients who died in an ICU have described experiencing a period of time between admission to the ICU and the decision to withdraw or limit treatment characterized by poor communication, uncertainty, ambiguity, and unanswered questions (Belanger, 2008). Health care providers have described this

period of time as a time to “wait and see,” and a time to let the patient “declare himself (Gutierrez, 2010; Lind et al., 2011).” During this time, communication might be infrequent and is often focused on factual information about vital signs and treatments (Lind et al., 2011). Often the trigger for a discussion about EOL care with family members is either conflict (Billings, 2011) or a sense that the patient has deteriorated to the point that a decision needs to be made (Norton & Bowers, 2001; Pieracci et al., 2008). Physicians often wait until they are fairly certain that the patient is not going to survive, expressing a need to build a strong case before discussing the prognosis and treatment options with family members (Gutierrez, 2010; Winzelberg, Patrick, et al., 2005). Although the ICU team members might talk among themselves about a patient being on a path to dying (N. Johnson et al., 2000), the family is often unaware that the patient is dying until they are called into a meeting to discuss goals of care. Often the physician schedules a family meeting to discuss goals of care already having made the decision that withdrawal of life support is the goal (Gutierrez, 2010). However, up until the time a meeting is scheduled, the family might have been hearing optimistic, ambiguous, or conflicting statements about prognosis leading them to interpret the discussion of EOL issues as abrupt (Lind et al., 2011).

The findings from this study demonstrated this phenomenon clearly in the case of the 59 year old African American woman with severe pulmonary hypertension and

right sided heart failure (P15). The daughter initially heard that the prognosis was guarded, but for the next 10 days, she heard encouraging information, including discussions of the possibility of taking her home. At the same time, the physicians and nurses all expressed little to no hope for her survival outside of the ICU. Once the physician approached the daughter about the poor prognosis and the need to discuss limitation of life support, the daughter was devastated and expressed mistrust and a fear that everyone was suddenly giving up on her mother.

Nurses are in a position to provide support for family members' decision-making needs and to help fill in this gap of communication. In this case, the nurses used strategies to build rapport and demonstrate concern for the patient and family members. However, the nurses could have provided leadership by being more proactive in assuring that this daughter was prepared. Strategies that nurses might have used include nurses exploring the daughter's understanding of the prognosis and alerting the physician team to the daughter's unrealistic goals. Other strategies that are within the scope of practice of the nurse are to explore the patient's values and goals by asking what kind of things she liked to do and what things were important to her. Other strategies include providing honest information about the patient's response to the illness and treatment, avoiding giving false hope by focusing only on positive findings. This includes pointing out that the patient is very ill and that the outcome is uncertain.

The concept of hope was interwoven throughout all of these strategies. Family members expressed that when nurses were optimistic, upbeat, pointed out positive signs, and reassured them that their loved one was in competent hands, they felt hopeful that their loved one would survive. When nurses demonstrated empathy and concern, used strategies to build rapport, and provided family members with timely and accurate information, they supported family members' ability to hope that the nurse would be someone upon whom they could trust and rely. When nurses supported decision making by engaging in discussions with family about prognosis, options, and consequences of options, and by assuring that the patient would be comfortable, they were able to help family members to reframe their hope from hope of cure to hope for a peaceful death. Although several family members expressed an appreciation for the nurse pointing out positive signs, an over emphasis on positive signs, in the face of a clearly poor prognosis, might have contributed to false hope.

#### **4.6.6 Limitations**

This study had several limitations. Because of the inherent uncertainty in determining a patient's prognosis early in the ICU stay, I did enroll several cases that did not involve a transition from curative to palliative care. In these cases either the patient survived or died before any EOL decisions were made. Five of the patients were discharged from the hospital without any EOL decisions. Although the data from these

cases do not contribute to understanding of EOL decision-making, they do contribute to the understanding of strategies nurses use with families to demonstrate concern, build rapport, demonstrate professionalism, and provide information.

My intent was to follow patient and family units over the trajectory of the ICU stay to assess how the strategies might have changed over that trajectory. Although I followed several patients for two weeks, I was only able to complete sufficient interviews for a trajectory analysis (three or more) on five of the 17 cases. The remaining 12 patients either died or were transferred before I was able to obtain a third interview, or the family members were not able to be reached for follow-up interviews. The study time period of two weeks also limited my findings, as several patients were in the ICU for more than two weeks. Three patients died several days or weeks after they had completed the study interviews; therefore, the process of EOL decision making occurred after they were no longer in the study.

#### **4.6.7 Implications for Practice**

The findings from this study indicate that ICU nurses are in a unique position to impact dramatically the experience of family members as they navigate the transition from curative to palliative care in the ICU. Although the concepts of demonstrating concern and building rapport are not novel to nurses, who are traditionally seen as caregivers, providing emotional support to their patients and family members (Cook et

al., 2003), these findings provide evidence to support that these strategies are crucial to the ability of these family members to cope with having a loved one who might be dying in the ICU. When nurses used simple strategies, such as making eye contact, facing the family, and coming to the phone when a family member called at night, they instilled trust and confidence, helping family members to cope with the changing condition of their loved one and to make decisions.

Nurses are in a position to enact the roles of advocate and information broker without having to overstep the bounds of their scope of practice. Family members expressed that they do not want to hear the prognosis from nurses. Yet they also did not want to receive vague or misleading information. Because of the expertise that nurses have in assessing the responses of family members to the illness and treatments, and because of the time that nurses spend with patients and family members at the bedside, nurses have a unique opportunity to build trust and rapport, to see the big picture, to collaborate with their physician colleagues, and to help family members to understand and process the information that they receive.

These findings also indicated that nurses sometimes engaged in approaches that were harmful to the family members and the patients. Being curt, telling a family member that their loved one cannot hear them, avoiding eye contact, and making family members wait unnecessarily for updates on the condition of their loved one are a few

examples of behaviors that eroded trust and made it more difficult for the family member to cope. Giving false hope might have made it more difficult for family members to accept that the patient was dying and might have delayed decision making.

The strategies identified are transferable to clinical practice. Nurses can and should be taught these specific skills that family members have identified as helpful. Nowhere is this more urgent than in the care of patients and family members at the EOL, where the emotional and financial costs are high.

#### **4.6.8 Implications for Future Research**

The knowledge generated from this study lays the foundation for future work grounded in empirical findings of what strategies family members find helpful. The findings from this project indicate that nursing approaches have the potential to affect the ability of family members to cope and make decisions. What is not known is how these nursing approaches affect the long term health and well-being of the family member and whether and how these approaches affect the nature of the decision that the family member makes. Further, no measures exist to determine the degree to which nurses use these strategies.

Questions for future work include:

1. What are the long term effects of nursing approaches on the health and well-being of family members?

2. What effect do nursing approaches have on the EOL decisions that family members make?
3. How can nurses best be supported in their attempts to use these approaches?

Future work will pave the way for incorporating these beneficial strategies as standards for nursing practice in this setting so that nurses will be able to base their practice on empirical evidence of what family members find helpful rather than on intuition and instinct. The ultimate goal of this work is to help family members make decisions that are consistent with their values and goals for EOL care.

#### **4.7 Conclusion**

This study provides empirical evidence that when interacting with family members of patients who are transitioning from curative to palliative care in the ICU, nurses use strategies that help family members cope, to have realistic hope, to have confidence and trust, to prepare for the impending loss, to accept that their loved one is dying, and to make decisions. This study also described harmful strategies in all five approaches that negatively affected the family members' trust and confidence in the nurses, increased their difficulty coping, and, in some cases, might have delayed decision-making. Few of these strategies have been previously described in the nursing literature.

When nurses used strategies to demonstrate concern and build rapport, family



members were able to have trust and confidence in the nurse. In some cases, this trust facilitated discussions about EOL decisions and goals of care. In addition, these strategies helped family members to maintain hope that the patient would receive competent care and that the family member would have someone upon whom they could trust and rely.

Strategies that demonstrated lack of concern or lack of rapport building, such as avoiding patient care; being rough with the patient; telling the family member that the patient cannot hear them; being rigid about visiting rules; avoiding engaging with family member; being impatient, curt, dismissive, or condescending; or asking the family member why they are not visiting more often created stress, anger, anxiety, difficulty coping, and lack of trust and confidence. These strategies should be avoided.

The findings from this study indicate that family members were comforted by nurses who had a calm, professional demeanor, demonstrated professional ethics and a positive morale, expressed confidence in the plan and gave consistent information, and respected the dignity and confidentiality of the patient. Further, although family members expressed that they liked feeling a personal connection with the nurse, they also appreciated the nurse leaving his/her personal problems out of their discussions. Family members described difficulty coping when they perceived that nurses lacked professionalism, such as demonstrating a poor morale or “chatting” about personal

topics within earshot of the family while they were on duty.

In enacting their professional role, nurses have the opportunity to be leaders in providing excellent EOL care by assessing the responses of patients and family members to the process of transitioning from curative to palliative care and by providing skilled and competent care in a calm and professional manner. In addition, acting as information brokers, nurses communicate their findings to physicians, alerting them when the patient shows signs of not responding to curative treatment and when family members have unrealistic goals and expectations.

These findings indicate that, although family members respected the knowledge and expertise of nurses, they did not expect to hear the prognosis from the nurse. Family members expected nurses to approach them with a calm and confident demeanor, to demonstrate a sense of higher duty to the patient and family member, and to avoid personal opinions or bias when discussing EOL decisions. Family members relied on nurses as a source of up to date information. In many cases this information consisted of factual data about the vital signs and laboratory values. Knowing these data sometimes helped family members to see the changing condition of the patient. In other cases, information only without interpretation might have contributed to a false sense of hope and even a delay in decision-making. When nurses explained why they were engaging in certain procedures or why a patient was receiving certain treatments, family members

reported increased confidence in the nurse, sensing that the nurse really knew what he/she was doing. Nurses at times gave vague, misleading, or inaccurate information leading to a lack of trust in that nurse. When family members called for an update and were told to call back, they experienced excruciating anxiety, worrying that their loved one might be doing poorly.

This study provides empirical evidence of specific nursing strategies that family members found helpful in their process of decision-making or in accepting the decision that they made. These strategies helped family members to prepare for and accept that their loved one was dying, make difficult decisions, and have closure. These strategies included, hinting at the prognosis, describing the severity of the illness, comparing the condition of the patient from one day to the next, verbalizing uncertainty, exploring values, discussing treatment options and consequences of decisions, reframing hope, at times expressing a desire not to inflict pain on the patient, and accepting whatever decision the family member made.

When family members perceived that they were being pushed to make a decision or that the nurse was not accepting of their decisions, they experienced lack of trust and difficulty coping. Failure to use strategies identified as helpful and use of negative strategies has the potential to create distrust, difficulty coping, and delay of decision-making. The consequences for the family member might be guilt, regret,

anxiety, traumatic stress reactions, and complicated grief; and the consequences for the patient might be prolongation of the dying process and unnecessary suffering.

The trajectory analyses indicated that nurses were more likely to engage in strategies to support decision-making later in the trajectory after the physician had begun discussion about prognosis with the family members. In addition, the nurses demonstrated flexibility in the use of these strategies based on where the patient was in the trajectory of dying and where the family was in their acceptance of the patient's death.

Use of strategies to demonstrate concern, build rapport, demonstrate professionalism, provide information, and support decision-making are tools that professional nurses used to support family members as they transitioned from curative to palliative care. It is imperative that nurses demonstrate flexibility in the use of these strategies, assessing where the family member is in their understanding and acceptance and tailoring the strategies to the specific needs of each family member. In addition, these strategies must not be used in a vacuum. Nurses must collaborate with their colleagues to be certain that the message the family member receives is clear and consistent.

## 5. Conclusion

### 5.1

In the United States 50% of people who die in hospitals, die during or after a stay in an intensive care unit (ICU) (Wunsch et al., 2009), and two thirds of ICU deaths involve a decision to limit treatment, either by withholding or withdrawing life-supportive therapy (Balboni et al., 2013; Balboni et al., 2007; Desteno et al., 2013; Prendergast et al., 1998; Prendergast & Luce, 1997). Because of the severity of their illness and the nature of treatments, up to 95% of ICU patients lack decision-making capacity (S. Cohen et al., 2005; Delgado et al., 2009; Goold et al., 2000; Hiltunen et al., 1999), leaving family members to make these difficult decisions.

End-of-life (EOL) decisions are by nature complex and emotionally charged. When faced with EOL decisions, family members of patients dying in ICUs face significant burden. The experience of making EOL decisions for a loved one in an ICU is associated with a high prevalence of symptoms of acute stress, anxiety, depression, post-traumatic stress disorder (PTSD), and complicated grief in family members (Azoulay et al., 2005; Pochard et al., 2005). The uncertainty of EOL decision-making might lead to feelings of guilt, regret, anxiety, and depression in family members who might they fear they are giving up too soon or that their loved one will experience pain (Abbott et al., 2001; Azoulay et al., 2005; Kirchhoff et al., 2002; Steinhauser et al., 2001, p. 204).

Nurses in the ICU are well positioned to provide decision-making support to family members because they spend extensive time periods with the patient and family, providing not only technical care but intimate personal care that allows nurses to develop trusting relationships with patients and families and to assess their needs (Puntillo & McAdam, 2006; Thelen, 2005). Nurses are able to observe the responses that family members have to the decision-making process. Nurses thus gain a unique perspective that places them in a position to provide support to family members who are making EOL decisions.

A systematic review of the nursing literature revealed that ICU nurses play an important role in facilitating the transition from curative to palliative care (Adams et al., 2011). This review indicated that, although nurses believe that their involvement is beneficial to patients and family members, data from the perspective of family members is sparse and consists mostly of retrospective data collected several months after the patient died (Adams et al., 2011). Better understanding of how nurses enact their roles in EOL care and how family members perceive the strategies used by nurses to be beneficial or harmful, has the potential to improve the overall quality of communication in EOL care and help more patients and families make decisions that are consistent with their values and goals for EOL care.

A pilot study was designed to test the feasibility of identifying an ICU patient

who was at high risk of dying and needing complex decision-making; interviewing family members, nurses, and physicians who were caring for that patient; and observing and recording family meetings held to discuss goals of care. I was able to identify a patient at high risk of dying and follow his progress over a period of five days as the family came to the decision to withdraw life support. I sat in on and recorded three family meetings and interviewed three nurses and one physician. I also interviewed the family as a unit on the last day.

I analyzed the content of the three family meetings to describe strategies used by health care professionals (HCP), including physicians and nurses, to facilitate the transition from curative to palliative care using the framework of Adaptive Leadership (AL). Adaptive Leadership is an organizational management framework based on complexity science (Thygeson et al., 2010) that has recently been applied to the health care context to propose HCP behaviors that mobilize and support patients and family members as they face and adapt to changes (D. E. Bailey, Jr., et al., 2012; Thygeson et al., 2010). Use of AL is consistent with current standards for EOL care in the ICU, which are based on the premise that family/patient-centered care and shared decision-making are ideals (Davidson et al., 2007; Truog et al., 2008).

In this study, I identified adaptive challenges and AL behaviors that facilitated family/patient centered care and shared decision-making. By providing information in

clear language, the HCPs ensured that the family members and the health care team had a shared understanding of the patient's prognosis and expected outcomes. By providing decision support, supporting realistic hope, and addressing work avoidance, the HCPs facilitated care that was centered on the goals of the patient and family. Use of AL behaviors supported the family's adaptive work as they navigated the transition from curative to palliative care.

Although this pilot study provided rich data about the ways that HCPs can support family members through the challenges of EOL decision-making, the data provided little evidence of the unique contribution made by nurses and how family members responded to nursing strategies. This study did demonstrate the feasibility of identifying a patient at high risk of dying and interviewing the family members during the ICU stay.

I designed my second study with the purpose of identifying specific nursing strategies that family members found helpful or unhelpful as they navigated the transition from curative to palliative care. The data for this study included interviews with the family members at intervals over the trajectory of the ICU stay, focused on their perceptions of nursing strategies that were helpful or not helpful and the family members hope for their loved one's survival. In addition, I included daily collection of data about the patient illness trajectory, perceptions of hope for the patient's survival



from the bedside nurse and the ICU attending or fellow, and observations of the ICU environment and family meetings.

The findings from this study indicated that nurses used numerous strategies with family members as they navigated the transition from curative to palliative care. These strategies were classified into five main approaches: demonstrate concern, build rapport, demonstrate professionalism, provide factual information, and support decision-making.

In each of these approaches, family members described nursing strategies that helped them to cope with the stress of having a loved one in the ICU, such as demonstrating empathy, listening, bending the rules to allow visitation, being willing to engage with the family members, providing them with frequent updates, discussing treatment options and consequences of decisions, and demonstrating acceptance of their decisions. These nursing strategies helped family members to feel that the nurse was a person they could trust, to have confidence in the nurse as a professional, to be prepared, to make decisions, to have closure, and to cope with the stress of the ICU environment.

The trajectory analysis indicated that nurses were able to demonstrate flexibility in the use of these strategies based on where the patient was in the trajectory of dying and where the family was in their acceptance of the patient's death. In one case where

the family was experiencing conflict with the physician and expressed feeling judged and misunderstood, the nurse used strategies to build rapport and focused the support decision-making strategies on accepting her decision and not reminding her how sick the patient was.

The trajectory analysis also suggested that the strategies built upon each other. The strategies to demonstrate concern, build rapport, and demonstrate professionalism helped the family member to have trust and confidence in the nurse and helped them cope with the stress of the ICU environment and the changing condition of their loved one. Providing information allowed family members to feel that they understood what was happening, to cope, to have confidence that the nurse knew how to care for the patient, and to trust that the nurse was a source of truthful, accurate information. All of these strategies helped to instill in the family members a sense of trust in the nurse, which then allowed the nurse to be a support to the family member in their decision-making. In the few instances where nurses were direct with family members about the poor prognosis and engaged openly in decision-making with the family, the family member expressed a close connection with the nurse and a trust that the nurse was saying what he/she was saying because he/she really cared.

Behaviors that are harmful to family members have not been described well in the literature. The findings from this study demonstrate that nurses sometimes engaged

in behaviors that family members described as harmful, including being rigid about rules, avoiding patient care, avoiding family members, being condescending or curt, providing inaccurate or vague information, rendering personal opinions or demonstrating lack of acceptance of EOL decisions. These behaviors led family members to lack trust and confidence in the nurse, to avoid asking questions, to feel judged, to experience anger and anxiety, and in some cases might have delayed decision-making. Further, these behaviors made it difficult for family members to cope. Several family members expressed anger, fear, and doubt, saying they were very uncomfortable leaving their loved one in the hands of a nurse whom they did not trust. These behaviors increased the stress that these family members were experiencing and made an already stressful situation worse for them.

## **5.2 Limitations**

This study had several limitations. Because of the inherent uncertainty in determining a patient's prognosis early in the ICU stay, I did enroll several cases that did not involve a transition from curative to palliative care. In these cases either the patient survived or died before any EOL decisions were made. Five of the patients were discharged from the hospital without any EOL decisions.

Although the data from these cases do not contribute to understanding of EOL decision-making, they do contribute to the understanding of strategies nurses use with

families to demonstrate concern, build rapport, demonstrate professionalism, and provide information.

I was also limited by contextual circumstances that allowed me to collect trajectory data on only five of the 17 cases. The remaining 12 patients either died or were transferred before I was able to collect sufficient data for trajectory analysis.

Another limitation was the time period of two weeks and the ability to interview family members at only three time points. Several patients were in the ICU for more than two weeks. Three patients died several days or weeks after they had completed the study interviews; therefore, decision-making may have occurred long after the patient was no longer enrolled in the study. Data from these longer term participants might have added to the understanding of the nursing strategies.

### ***5.3 Implications for Clinical Practice***

The findings from this research indicate that nurses play a vital role in the care and support of family members of patients transitioning from curative to palliative care in the ICU. I was able to identify specific behaviors that are transferable into clinical practice and can be taught to nurses.

Although the concepts of demonstrating concern and building rapport are not novel to nurses, who are traditionally seen as caregivers, providing emotional support to their patients and family members (Cook et al., 2003), these findings provide evidence to

support that these strategies are crucial to the ability of these family members to cope with having a loved one who might be dying in the ICU. When nurses used simple strategies, such as making eye contact and facing the family, they instilled trust and confidence, helping family members to cope with the changing condition of their loved one and to make decisions.

These strategies provide a guide for nurses in enacting their roles as patient advocate and information broker without having to overstep the bounds of their scope of practice. Family members expressed that they do not want to hear the prognosis from nurses. Yet they also did not want to receive vague or misleading information. Because of the expertise that nurses have in assessing the responses of family members to the illness and treatments, and because of the time that nurses spend with patients and family members at the bedside, nurses have a unique opportunity to build trust and rapport, to see the big picture, to collaborate with their physician colleagues, and to help family members to understand and process the information that they receive.

These findings also indicated that nurses sometimes engaged in approaches that were harmful to the family members and the patients. Being curt, telling a family member that their loved one cannot hear them, avoiding eye contact, and making family members wait unnecessarily for updates on the condition of their loved one are a few examples of behaviors that eroded trust and made it more difficult for the family

member to trust and cope. Giving false hope might have made it more difficult for the family member to accept that the patient was dying and delayed decision making.

These data were collected in a large magnet teaching hospital on two units that are very supportive of palliative care and where other researchers were conducting palliative care research. Yet, of the eight patients who died in the ICU (P3, P4, P5, P8, P11, P12, P14, P15), five were in the ICU for more than ten days before they died (P4, P5, P11, P12, P15), and four were in the ICU for more than two weeks. Of those five patients with prolonged stays, two had life support withdrawn prior to death (P4, P11), and the other three died while on mechanical ventilation with a DNR in place (P5, P12, P15).

The reasons for delays in decision-making are complex and multifactorial and might involve the cultural beliefs and preferences of the family members, the cultural environment of the ICU, and the behavior of the physicians and nurses. The medical literature describes many potential causes for delays in EOL decision-making, including being overly optimistic with the family (Barclay et al., 2007), delaying discussions about goals of care until the physician is certain of the prognosis (Gutierrez, 2010; Kryworuchko et al., 2012; Lind et al., 2011), deferring the discussion to another provider (Norton & Bowers, 2001), being unavailable to the family (Lind et al., 2011), using ambiguous language, and euphemisms (Gutierrez, 2010), defining death as failure, making surrogate feel responsible for the decision, and abandoning the family

(Wiegand, 2006a, 2006b), fragmentation of care, and providing technical information only without discussing goals of care (Wiegand, 2006b). This literature also describes cultural differences; family tensions (Anselm et al., 2005); and conflict within families, between the family and the HCPs, and conflict among HCPs (Abbott et al., 2001; Breen et al., 2001) as possible causes of delay in decision-making.

Some of these factors were evident in these data. In one case (P15), the attending physician stated to me that he/she believed that the prognosis was poor but expressed that he/she did not want to discuss it with the family, preferring to leave these discussions until the new attending began rotation the following day. In another case (P12) the family expressed conflict and a loss of trust in the physicians after a physician told them that they never should have brought the patient to the hospital. In a third case (P4) the husband had made it clear that he wanted everything done because the patient was the mother of a teenaged girl who wanted to live as long as she could for her daughter. The wife of P5 expressed distrust and a sense that she was being pushed by physicians and nurses to make a decision. She had told her husband that she would do everything to keep him alive. The wife of P11 expressed that she wanted to continue treatment as long as her husband was showing any response to the treatment. In this case, the attending physician and nurses had several discussions with her that were riddled with ambiguous language leaving her feeling in limbo.

What is evident from these data is that, in some cases, clear discussions about goals of care did not occur until late in the trajectory of the ICU stay. Although the physician is ultimately responsible for making a medical diagnosis, delivering the initial news about a poor prognosis, and determining treatment options, nurses have a role in the decision-making process. Early in the ICU stay, before a prognosis has been reached and communicated the family, nurses enact the roles of supporter and information broker by using approaches to demonstrate concern, build rapport, demonstrate professionalism, and provide information. These strategies help family members to manage their emotions, cope with the stress of the ICU stay, develop confidence in the skill of the nurses and physicians, and to trust.

Further along in the trajectory of the ICU stay, nurses sometimes develop an awareness that a patient is not going to survive before the physician is ready to disclose the prognosis to the family member (McMillen, 2008). The role of the nurse in this situation expands to include the role of advocate. As an advocate, a nurse has the responsibility to collaborate with and provide his/her physician colleagues with a nursing assessment of the patient's condition, response to treatment, and the family member's understanding of the condition of the patient and readiness to begin discussions about EOL decision-making. In addition, as an advocate, the nurse's presence at meetings between the physicians and the family members, allow him/her to



reinforce and clarify the information given by the physician. Nurses may also call for a family meeting or request a consult with the palliative care team, if such a team exists in that institution. In some situations, a nurse might choose to request an ethics consultation if the situation is not resolved by talking with the physician directly. Although nurses might be tempted to remedy the perceived communication gap by directly telling the family members that the prognosis is poor, such strategies have the potential to cause stress and conflict for family members and might further delay decision making (IOM, 2011; Nelson, Puntillo, et al., 2010).

Once the prognosis has been disclosed to the family member, nurses enact the roles of supporter, information broker, and advocate by continuing to demonstrate concern, build rapport, demonstrate professionalism, and provide information. In addition, nurses enact the role of advocate by helping the family members to understand what the prognosis means for them and their loved one. This might include discussing goals of care, quality of life, consequences and trade-offs of decisions, and reframing their hope from hope of cure to hope for a peaceful death.

The strategies identified in this research are transferable to clinical practice. Nurses can and should be taught these specific skills that family members have identified as helpful. Nowhere is this more urgent than in the care of patients and family members at the EOL, where the emotional and financial costs are high.

## ***5.4 Implications for Research***

The findings from these studies indicate that nurses play a critical role in supporting family members through the trajectory of treatment decisions in the ICU that might involve the transition from curative to palliative care. Studies from the perspective of nurses identified several roles that nurses play in the EOL decision-making process, including supporter, information broker, and advocate. In enacting these roles, nurses use several approaches and a multitude of strategies. Few studies have focused on the perspective of family members and their responses to nursing strategies and those that did were mostly retrospective. To my knowledge, the study in chapter 4 was the first to follow family members prospectively and longitudinally in an ICU environment over the trajectory of transition from curative to palliative care to explore how they perceived and responded to nursing strategies.

The knowledge of what nursing strategies family members find acceptable and helpful as well as what behaviors they might find unacceptable or harmful lays the groundwork for future work to improve the use of helpful strategies and decrease those that are unhelpful or harmful. These findings suggest that family members and patients on a trajectory of transition from curative to palliative care are best served by nurses who enact the roles of supporter, information broker, and advocate by using strategies

that demonstrate concern, build rapport, demonstrate professionalism, provide information, and support decision-making.

These data suggest that nursing approaches might have a powerful impact on the health and well-being of family members who are adapting to the new reality that their loved one might die. Because I did not follow the family members through the period of bereavement and because I did not use any measures to assess well-being, anxiety, depression, acute stress, or grief, I am not able to infer how the nursing approaches affected the family member's well-being over time.

These data also raise the question of how the nursing approaches affect the ultimate decision that the family member makes. The participants did not indicate that the nurses influenced their decisions. However, it is possible that family members who developed trusting relationships and felt they were supported might have found it easier to make decisions to limit or withdraw life support.

Questions for future research include;

1. What are the long term effects of nursing approaches on the health and well-being of family members?
2. What effect do nursing approaches have on the EOL decisions that family members make?
3. How can nurses best be supported in their attempts to use these approaches?

## **5.5 Closing**

Nurses use an array of helpful strategies to support family members of patients transitioning from curative to palliative care in the ICU, yet they also engage in behaviors that have the potential to cause harm to the family members and to delay decision-making. These strategies need further exploration to determine how they affect the overall health and well-being of patients and family members and how they can best be disseminated to nurses in clinical practice.

## **Appendix A: Interview Guides**

### ***Family Member Interview at Study Entry***

**Directions:** This interview guide will be conducted within the day of enrollment into the study.

**Focus:** The focus of this interview is to build rapport and allow the participant to describe the experience of having their loved one admitted to the ICU. In addition, the interviewer will explore for any interactions or communications with nurses

#### **Main questions:**

- Introduction: Tell me about how your loved one came to be in the ICU.
- Question: I would like you to tell me what it was like for you when you visited the ICU for the first time.

#### **Prompts:**

- When you visited
  - Who talked to you?
  - What did they say?
  - When that was happening, what thoughts did you have?
  - What were your feelings at that time?
- Explore any comments about the nurses
- Ask about trust or confidence in nurse
- What things have the nurses said or done that have made it easier for you?
- What things have the nurses done that have made it harder or you?
- What things have the nurses said or done to encourage you to ask questions or talk about your concerns?
- What things have the nurses have said or done that have discouraged you from asking questions or talking about your concerns.
- How hopeful are you right now on this scale?
- What are you hopeful for?
- Sometimes nurses use their own personal stories when talking to people. Tell me about your experience with that in the ICU.

#### **Field notes**

I will keep notations of observations of the setting, including non-verbal communication and overall impressions or events that occurred during the interview.

## Follow-up Family Member Interview

**Directions:** This interview will be conducted Up to two times during the participant's enrollment in the study

**Focus:** The focus of this interview is to allow the participant to continue to tell the story and describe their perspectives of the nursing strategies used.

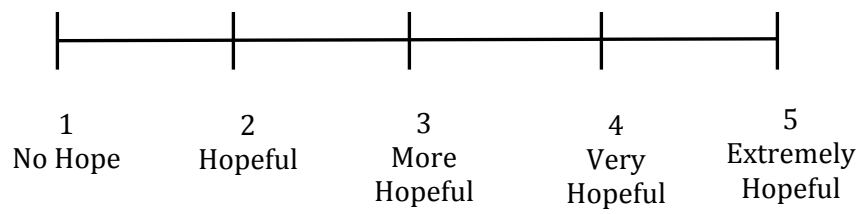
### Main questions.

- Introduction: Tell me what happened since we last talked (name the time and day)
- The last time we talked, you said (briefly highlight main topics)
- Tell me about anything new or different that the nurses are doing or saying

### Prompts

- Explore any comments about the nurses
  - What things have the nurses said or done that have made it easier for you?
  - What things have the nurses done that have made it harder for you?
  - What things have the nurses said or done to encourage you to ask questions or talk about your concerns?
  - What things have the nurses have said or done that have discouraged you from asking questions or talking about your concerns.
- How hopeful are you right now on this scale?
- What are you hopeful for?
- Sometimes nurses use their own personal stories when talking to people. Tell me about your experience with that in the ICU

## Appendix B Hope Line



## Appendix C: Demographics

### ***Study Entry Patient Demographics***

Participant ID\_\_\_\_\_

Diagnoses\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Age\_\_\_\_\_

Gender\_\_\_\_\_ (Female = 1, Male = 0)

Race/ethnicity\_\_\_\_ (0=Caucasian, 1=AA, 2=other)

SES (0 = Medicaid, Medicare without supplement, or No insurance

1 = Private Insurance or Medicare plus supplement )

### ***Study Entry Family Participant Demographics***

Participant ID\_\_\_\_\_

Age\_\_\_\_\_

Gender\_\_\_\_\_ (Female = 1, Male = 0)

Race/ethnicity\_\_\_\_ (0=Caucasian, 1=AA, 2=other)

Education \_\_\_\_\_

Past experience with ICU\_\_\_\_\_

Relationship to patient\_\_\_\_\_

Religion or faith\_\_\_\_\_



## Appendix D: Patient Data Collection Tool

### ***Daily Tracker of Illness, Prognosis, and Treatment Characteristics***

#### **Treatments**

Ventilator

Type: \_\_\_\_\_

Settings: FIO2: \_\_\_\_\_ RATE: \_\_\_\_\_ PEEP: \_\_\_\_\_ Pressure support \_\_\_\_\_

Vasopressors

Tube Feeding (circle)

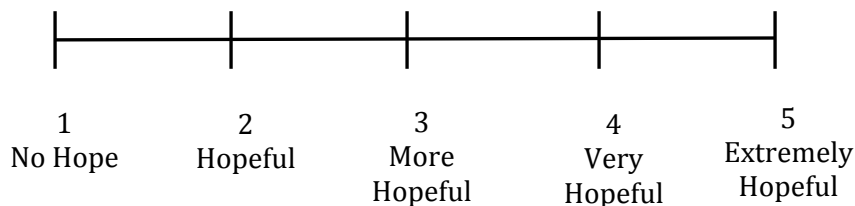
N/G, dohoff, PEG

Discussions with family about decision-making \_\_\_\_\_

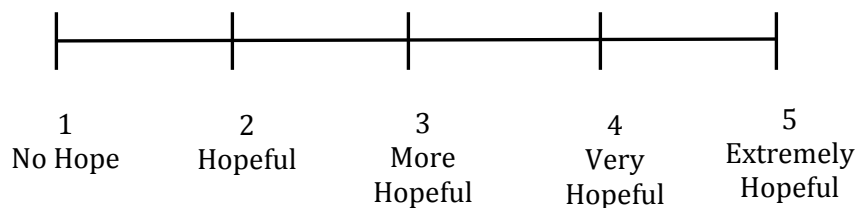
Changes in regimen or plan \_\_\_\_\_

Significant Diagnostic tests \_\_\_\_\_

#### **Nurses' perception of prognosis/Hope for recovery**



#### **Physician's perception of prognosis/Hope for recovery**



## **Appendix E Field Notes**

### ***Observations of Family Conferences:***

The family meetings will be audio recorded for later transcription and coding. In addition, field notes will be used to describe contextual details that would not be available in the audio recording.

Physical Space

Participants

Seating arrangement

Demeanor of the person leading the meeting

Demeanor of the family members participated and how did they participate?

Where did the nurse sit/stand?

How did the nurse use body language with the family in the meeting?

What emotions were demonstrated?

How long did the meeting last?

How did people leave the meeting when it ended? Was there any additional body language or interaction?

### ***Observations of Unit Environment***

How the nurses communicate with physicians, with other nurses, and with families about of EOL decision-making.

## **Appendix F: A Priori Codes Defined**

### ***Nursing Strategies***

#### **Educate**

Inclusion: Provide information about the underlying disease process including description of the overall big picture.

Exclusion: Explain equipment, give lab results without interpretation

Exemplars: Explain underlying frailty and poor functional status prior to hospitalization as a poor prognostic indicator.

Close but no: Educate about how to care for a condition at home when it is obvious the patient is not going home

#### **Explain equipment**

Inclusion: Explain the function and purpose of the equipment

Exclusion: Focus on managing equipment to the exclusion of communicating with family

Exemplars: Explain to the family that the ventilator is breathing for the patient.

Close but no: Acknowledging presence of equipment but not explaining its function.

#### **Interpret medical terms**

Inclusion: Explain to the family what the physician has said

Exclusion: Tell the family something different than what the physician said; tell the family of a poor prognosis before the physician has spoken to the family

Exemplar: After the physician has met with the family in the presence of the nurse, the nurse asks the family to repeat what they understood and then clarifies any misunderstanding.

Close but no: After a meeting in which the nurse was not present, ask the family what the physician told them and then tell the family what the nurse's interpretation is of the condition of the patient.

## **Interpret the meaning of information**

Inclusion: Give information about lab values, vital signs, x-ray results, and explain what they mean in the big picture

Exclusion: Give information only with no explanation

Exemplar: Explain to the family of a frail chronically critically ill patient that a very low albumin is a sign that the patient lacks sufficient protein to heal and is contributing to the excess fluid in the tissues and lungs. Explain that once an albumin is this low, it is very difficult to correct

Close but no: Tell family that the BP is better but do not explain what that means in the overall picture

## **Give personal opinion**

Inclusion: Give the family a personal or religious based opinion about the rightness or wrongness of the treatment decisions

Exclusions: explain the outcomes of decisions, such as what might happen if the decision were made to continue treatment versus discontinue treatment

Exemplar: Say to a family member, "I think you are torturing him and you should stop" this. Or say, "if this were my mother, I would not stop no matter what."

Close but no: Tell the family that whenever the nurse turns or suctions the patient, he shows signs of pain and that it is difficult to watch him in pain.

## **Give meaningless information**

Inclusion: Give the family information that does not contribute to their understanding of the prognosis and might be misleading

Exclusion: Explain the meaning of information

Exemplar: Tell the family that the blood pressure is better without explaining that the BP is better because the patient is actually on a higher dose of Levophed, not because the patient is improving.

Close but no: Give results that are consistent with prognosis, such as more difficulty keeping the BP up, but not explaining what that means in the big picture

## **Give poor prognosis**

Inclusion: Discuss the poor prognosis with the family before the physician has done so.

Exclusion: Interpret what physician has said, discuss implication of treatment decisions, or explain significance of lab results.

Exemplar: Tell the family member before the physician has spoken about prognosis that the patient is not going to survive.

Close but no: Drop hints that the patient might not be doing well, recommending that the family ask the physician what the prognosis is.

### **Defer questions**

Inclusion: refuse to answer any questions about the patient's condition, instead deferring to the physician.

Exclusion: Reframing questions to assess family's understanding and emotional responses

Exemplar: A family member asks what it means that the patient needs more ventilator support and the nurse says, "I'll get the doctor to answer that question for you.

Close but no: Answer questions but then encourages family to set up meeting with physician to discuss further.

### **Give false hope**

Inclusion: Giving the family encouragement that the patient will survive when it is obvious that the patient has a very poor prognosis

Exclusion: Encouraging family when it does appear that the patient will survive

Exemplar: Reassuring the family that the patient will get through this and soon be able to go home

Close but no: Focusing on positive signs

### **Coordinate family meetings**

Inclusion: Actions the nurse does to arrange and set up a family meeting

Exclusion: Suggesting a family meeting but not doing anything to coordinate it

Exemplar: Nurse requests a family meeting, sets up a mutually agreeable time for family and physician, secures a room, and sits in on meeting

Close but no: Nurse asks for a palliative care consult

## **Consult other disciplines**

Inclusion: Actions taken to involve other disciplines such as social work, chaplaincy, palliative care or ethics

Exclusion: Suggest and coordinate family meeting

Exemplar: request palliative care consult. Ask the social worker or chaplain to visit the family

Close but no: Tell the family to ask the physician for a palliative care consult

## **Facilitate communication between medical team and family**

Inclusion: Any other actions besides coordinating family meetings actions that encourage communication between the medical team and the family.

Exclusion: coordinating a family meeting

Exemplar: Request that a physician speak to a family or prompt family in what to ask physician.

Close but no: Tell the family that they need to ask the physician these questions.

## **Include family**

Inclusion: Take time to talk to family, allow family to ask questions, explain what is going on, allow family to be with patient and encourage them to be involved in care

Exclusion: Ignore family, focus on technical aspects of care, give the family the impression that they are in the way.

Exemplars: The nurse introduces him/herself, asks if the family has questions, assesses family needs, explains and clarifies information, describes the care of the patient, and allows and encourages family to touch and be involved in care of patient.

Close but no: Nurse says, Hi my name is... I'll be here if you have questions but then busies him/herself with technical care.

## **Show respect**

Inclusion: Encourage rituals that are important to them, and encouraging storytelling and life review, allow family time to process information, and support decisions.

Exclusion: Nurse discourages rituals and tells family not to bother talking because that patient can't hear. Nurse tells family that he/she disagrees with decisions. Nurse pressures family to make a decision.

Exemplars: Nurse encourages families to bring in items that are important to them and to the patient, such as pictures and religious icons and encourages the family to talk to the patient and engage in family storytelling. Nurse assures family that he/she is accepting of whatever decisions they make

Close but no: Allow family to bring in important items but tells them they need to take them home with them. Offers to contact priest without asking what their religious preference is.

### **Prepare family**

Inclusion: Discuss possible outcomes with the family

Exclusion: Give false hope

Exemplar: When family asks how a patient is doing, the nurse explains the condition and the possibility that the patient might or might not survive the hospitalization. The nurse explains that if the patient survives there is a possibility of needing long-term care.

Close but no: The nurse tells the family that the patient is dying and that treatment is futile.

### **Demonstrate empathy**

Inclusion: acknowledge feelings and provide emotional support

Exclusion: Reject or deny importance of feelings

Exemplar: When family member expresses fear, anxiety, or anger, identify and explore the emotion. Use of NURSE mnemonic (Back, Arnold, Baile, Tulskey, & Fryer-Edwards, 2005)

Close but no: Acknowledge emotion but use blocking behaviors, such as changing the subject to the physical condition of the patient to avoid exploring the emotion (Back et al., 2005).

### **Block communication**

Inclusion: Nurse does not respond to family members request for information or to an emotional cue. Instead nurse ignores or redirects conversation

Exclusion: Respond to and explore emotion

Exemplar: Family member asks if patient is going to die and nurse gives information about the BP and recent lab work and recommends that the family ask the physicians

that question.

Close but no: Family member asks is patient going to die and nurses says it sounds like you are really concerned about that, let me ask the doctor to speak to you about it.

### **Explore goals**

Inclusion: Asking family what the patient would want if he/she were able to speak.

Asking about what things were important to the patient, what were the patient's values.

Ask if the patient had ever expressed feelings about being on life support or about the importance of QOL.

Exclusion: Giving own personal opinions about what is right or wrong

Exemplar: A family member tells a nurse that the doctor told her that the patient would not recover and if he did would end up in a nursing home. She tells the nurse she doesn't know what to do. The nurse asks the person to talk about the things that were important to the patient and after listening and responding to emotions, the nurse then asks what the patient would have wanted.

Close but no: Asking if the patient has an advance directive.



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## Biography

Judith Adams was born in New Haven, Connecticut on September 22, 1958. She earned an associate degree in nursing from Quinnipiac University in Hamden Connecticut in June of 1980 and a bachelor of science in nursing from Pennsylvania State University in State College, Pennsylvania in December of 1987. She then pursued a master's of science in nursing from Georgetown University in Washington, DC, graduating in April 1994.

Since beginning her graduate studies at Duke University School of Nursing, she has received two grants from the National Institutes of Health, an individual national research service award (NRSA) as a pre-doctoral fellow and a clinical and translational science award (CTSA). She also received grant funding through the Hospice and Palliative Nurses Foundation. She has published three articles in peer-reviewed journals and has a fourth in press:

1. **Adams, J. A.,** Bailey, D.E. Jr., Anderson, R. A., & Docherty, S. L. (2011). Acute care nurses' involvement in end-of-life decision-making: A systematic review of the literature. *Nursing Research and Practice*. 2011: Article ID 527834. PMCID: [PMC3184494](https://pubmed.ncbi.nlm.nih.gov/3184494/)

2. **Adams, J. A.**, Bailey, D. E., Anderson, R. A., and Galanos, A. N. (2012). Adaptive Leadership: A novel approach for family decision-making. *Journal of Palliative Medicine*, 16(3), 326-329. DOI: 10.1089/jpm.2011.0406 PMID: [22663140](https://pubmed.ncbi.nlm.nih.gov/22663140/)
3. Bailey, D. E., Docherty, S.L., **Adams, J. A.**, Carthron, D.L., Corazzini, K., Day, J. R., Neglia, E., Thygeson, M., & Anderson, R. A. (2012). Studying the clinical encounter with the Adaptive Leadership framework. *Journal of Healthcare Leadership*, 2012(4), 83-91. <http://dx.doi.org/10.2147/JHL.S32686>
4. **Adams, J. A.**, Bailey, D. E., Anderson, R. A., & Thygeson, M. (2013, in press). Finding your way through EOL challenges in the ICU using Adaptive Leadership behaviours: A descriptive case study. *Intensive and Critical Care Nursing*.